

# NOW

ANNUAL REPORT FY 2018 ▶



National  
Kidney  
Foundation®



# NKF NOW:

## Advancing Our Momentum

Dear Friends and Supporters:

We are addressing the rise in kidney disease with breakthroughs that are changing the world of kidney health—*Now*. We can point to this year with pride, not just in our organization, but in the people who are making these breakthroughs happen. Across the board, we've been making significant gains with research, treatment, advocacy, awareness, and patient engagement.

Advancing new and improved treatments for kidney disease is a top National Kidney Foundation priority. Accelerating new clinical trials and treatments for early-stage chronic kidney disease (CKD) is now within reach. NKF spearheaded a joint scientific workshop with the Food and Drug Administration and the European Medicines Agency to review the results of a major, multi-year meta-analysis examining the largest compilation of data ever collected on CKD. Leading researchers, clinicians, and scientists from throughout the world gathered to review this data on nearly two million patients to discover new end points for clinical trials, which may accelerate and improve treatments to reduce the risk of progression to kidney failure and improve the lives of patients with kidney disease.

NKF is removing barriers to early detection and diagnosis of CKD by collaborating with the American Society for Clinical Pathology, the nation's leading laboratories, and clinical laboratory societies. This new collaboration will help standardize the tests used to identify CKD, improve comparison of test results between laboratories, increase early recognition of the disease, and promote patient awareness. A component of this new initiative is the new "Kidney Profile," which will simplify ordering of the tests needed to identify and diagnose CKD.

Landmark legislation initiated by NKF and introduced in Congress as H.R. 3867 will help doctors and patients identify and treat CKD earlier to achieve better patient outcomes. The legislation seeks to demonstrate, through a Medicare pilot program, that early detection of CKD,

combined with effective and coordinated care that engages patients in the decision-making process, can not only improve clinical results, but also lower healthcare spending.

NKF's THE BIG ASK: THE BIG GIVE platform continues its successful roll-out with expanded in-person trainings held at leading transplant centers nationwide. All platform resources are free and designed to teach kidney patients, or their advocates, how to make a "big ask" to their friends, loved ones, or community to consider making a "big give" of a life-saving living organ donation. And a new public service announcement series for the platform was launched, which focused on the African-American community, a key underserved community with higher rates of kidney disease but lower rates of kidney transplantation.

NKF Kidney Walks had their most exciting year to date, as their national corporate partners exceeded \$1 million in contributions for the first time ever, while tens of thousands of attendees across the nation got on the move against kidney disease and walked for kidney health.

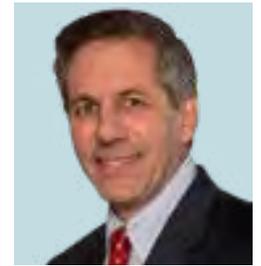
And our new Kid Ambassador, *America's Got Talent* singing sensation—and kidney transplant recipient—Angelica Hale, has joined the team and is hard at work advocating for living donation on Capitol Hill, appearing in a series of NKF PSAs, getting out the message of kidney health through media interviews, and appearing in a Facebook Live event with Members of Congress. Angelica's powerful example and message are energizing people across the country.

These "Top Takeaways," featured inside, don't tell the whole story of NKF. The rest of this report shows a national team hard at work across the country, getting the word out, serving patients and families, breaking barriers and new ground—*Now*.

The time for change is now, and thanks to your generous support, it is happening *Now*.

*With gratitude,*

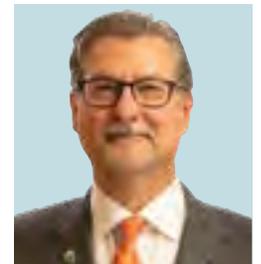
Art, Mike, and Kevin



**Art Pasquarella, CRE**  
Chair



**Michael J. Choi, MD**  
President



**Kevin Longino**  
Chief Executive Officer

# TOP TAKEAWAYS FROM NKF THIS YEAR

*Changing the World of Kidney Health*

## Clinical Trials—When “End Points” Can Mean a New Beginning for Early-Stage CKD Treatments

NKF is determined to improve outcomes for patients with chronic kidney disease (CKD). We are breaking barriers in research on early-stage kidney disease treatments by accelerating clinical trials, because new treatments need to be made available to doctors and patients. NKF spearheaded a landmark scientific workshop with the Food and Drug Administration (FDA) and the European Medicines Agency (EMA) in March 2018. Titled *Change in Albuminuria and GFR as End Points for Clinical Trials in Early Stages of Chronic Kidney Disease*, attendees reviewed data collected from nearly two million patients supporting the use of earlier markers of kidney disease progression as end points in clinical trials for early stages of CKD. These clinical trials may lead to treatments that will improve the lives of people with kidney disease. The meta-analysis and recommendations from the workshop will be reported in a series of articles to be published in late 2018 and 2019.

In attendance were 150 stakeholders: study investigators who contributed data for the analysis; representatives from the FDA, EMA, National

Institutes of Health (NIH), and Centers for Medicare and Medicaid Services (CMS); clinical trial and laboratory experts; professional associations and guideline groups; pharmaceutical industry researchers; and patients affected by CKD. Publicity efforts to promote the conference reached 16.6 million people, and a video reel highlighting the key takeaways from the conference and the potential impact on kidney patients was released on NKF’s internal and external channels.

“For more than two years, some of the world’s leading researchers have compiled and analyzed extensive data which will be useful in both clinical practice and future clinical trials for kidney disease. The work presented over the past two days will help move us closer to developing medications to arrest kidney disease in its earliest stages, before patients progress to end-stage renal disease and are faced with life-threatening complications and only dialysis or a transplant as options to survive.” ▶ **Andrew S. Levey, MD, workshop chair and Professor of Medicine, Tufts University School of Medicine**

See page 8 to find out more about NKF research initiatives.



# CKDintercept<sup>®</sup> Laboratory Engagement Plan—Saving Lives Through Early Detection

NKF is changing the way CKD is detected and treated. NKF, the American Society for Clinical Pathology (ASCP), and the nation's leading laboratories and clinical laboratory societies have announced a new collaboration to remove barriers to testing for CKD. Led by NKF, this effort will help standardize the tests used to detect CKD, improve comparison of test results between laboratories, increase early recognition of the disease, and promote patient awareness of the condition. The alliance is believed to be the first to combine the resources and talents of leading clinical laboratory societies, multiple laboratory providers, and a patient advocacy group to advance improvements in CKD laboratory testing.

ARUP Laboratories, BioReference Laboratories, Inc., LabCorp, Mayo Medical Laboratories, Memorial Sloan Kettering Cancer Center, Quest Diagnostics, and Sonic Healthcare USA have aligned with the initiative's recommendations and made significant investments to implement changes in their laboratory ordering, reporting, and billing systems. In addition, laboratory partners are working together to provide all clinicians ordering labs with information about CKD. Any laboratory can join and help execute the suggested changes.

A component of the collaboration is the recommendation of a new "Kidney Profile" for CKD assessment and diagnosis (see sidebar). Currently, 94 percent of patients with high blood pressure and 61 percent with diabetes are not receiving both tests necessary to detect and assess CKD, as recommended by clinical practice guidelines, despite these being the top two risk factors for developing CKD.



*NKF thanks ASCP for its partnership in developing the related materials for patients and professionals, and the following organizations for working with NKF to improve assessment of individuals at risk for kidney disease: American Association of Bioanalysts, American Association for Clinical Chemistry, American Clinical Laboratory Association, ARUP Laboratories, BioReference Laboratories, Inc., Clinical Laboratory Management Association, LabCorp, Mayo Medical Laboratories, Memorial Sloan Kettering Cancer Center, National Independent Laboratory Association, Quest Diagnostics, and Sonic Healthcare USA.*

## "Kidney Profile"—Simplifying Tests to Detect Kidney Disease Early

The new "Kidney Profile" follows evidence-based clinical practice guidelines,<sup>1</sup> which recommend two tests for CKD assessment. Laboratories adopting the Kidney Profile will simplify ordering of the tests needed to detect and diagnose CKD by pairing them together under one heading on the laboratory requisition form or electronic health record order. Such streamlining of CKD test ordering could help to eliminate the need to search for each test separately and increases the ease of monitoring results. The Kidney Profile also makes it easier for people at risk for CKD to better understand and track their health.

The Kidney Profile combines the estimated glomerular filtration rate (eGFR), which assesses kidney function, and urine albumin-creatinine ratio (ACR), which assesses kidney damage. Both are used to test for and diagnose CKD in primary care settings. People living with CKD have an elevated risk for cardiovascular disease. *This combination of eGFR and ACR testing has been shown to be a strong predictor of both cardiovascular mortality and kidney failure risk.* The Kidney Profile is now available through LabCorp and BioReference Laboratories, Inc. Quest Diagnostics, Sonic Healthcare USA, ARUP Laboratories, and the remaining laboratories will have the Kidney Profile available later this year.

Resources for pathologists and laboratory professionals about the diagnosis of CKD, as well as information regarding this important collaboration, the CKDI Laboratory Engagement Plan, and other professional resources are available at: [kidney.org/CKDintercept/laboratoryengagement](http://kidney.org/CKDintercept/laboratoryengagement)

"... screening within the primary care setting is crucial in identifying patients with early-stage renal disease. Aligning with the National Kidney Foundation, the American Society for Clinical Pathology, and other national laboratories to standardize testing will enable physicians to more easily identify and diagnose patients at risk, and begin monitoring and appropriate therapy before disease progresses. We are pleased to be part of this initiative." ▶ **James Weisberger, MD, Executive Vice President, Chief Medical Officer, Laboratory Director at BioReference Laboratories, an OPKO Health Company**

1. Inker LA, et al. KDOQI US commentary on the 2012 KDIGO clinical practice guideline for the evaluation and management of CKD. *American Journal of Kidney Diseases*. 2014;63(5):713-735.

## Legislative Breakthroughs—Personal Stories Move Congress to Act

In Congress and in state legislatures throughout the country, NKF is the voice of kidney patients and living donors, opening new doors through government action. Our advocates, Government Relations team, and congressional supporters are making kidney disease a top priority on congressional agendas. The NKF-initiated landmark bill H.R. 3867 was introduced in Congress in September 2017 and is supported by NKF's Kidney Advocacy Committee (KAC) liaisons, who use their stories to champion the bill. (See page 25.) The legislation's long-term goal is to help doctors and patients across the country detect and treat CKD earlier to

achieve better patient outcomes. H.R. 3867 will direct the Secretary of Health and Human Services (HHS) to design a voluntary pilot program that ties Medicare payment to improvements in early detection of CKD and the quality of care these patients receive.

NKF advocates continue to build support for the federal Living Donor Protection Act (H.R. 1270), which prohibits insurance and job discrimination against living donors. Encouraged by local NKF advocates and NKF's Government Relations team, states are passing their own versions of the legislation. Idaho became the first state in the nation to pass the landmark bill,

supported by Governor Butch Otter and NKF of Utah and Idaho, called The Living Organ Donor Protection Act (S. 1302), which makes insurance discrimination against living donors in the state illegal. In FY18, NKF of Colorado advocates worked on passing the groundbreaking H.B. 1202, which provides paid leave for employees who would like to become living organ donors. This legislation will provide private employers with a voluntary tax credit of 35 percent of an employee's salary to cover up to 10 business days of paid leave. The bill, HB18-1202 Income Tax Credit Leave Of Absence Organ Donation, was signed by Governor John Hickenlooper.

The 5th Annual Kidney Patient Summit in Washington, DC put faces on the issue of kidney disease for Members of Congress. Some 100 patient advocates, led by NKF's Kidney Advocacy Committee, converged on Capitol Hill to urge their lawmakers to support legislation to improve the lives of people with kidney disease. Our first-ever NKF Kid Ambassador, Angelica Hale, took Capitol Hill by storm, interviewing Members of Congress in a Facebook Live, and performing for the NKF Congressional Awards Reception. (See pages 25, 26, and 28.) (And find out the latest on legislation on page 22.)



# THE BIG ASK: THE BIG GIVE (BABG)—Making More Living Donations Possible

The BABG platform teaches kidney patients, or their advocates, how to make a “big ask” to their friends, loved ones, or people in their community to consider making a “big give,” a living organ donation. Building upon a highly successful pilot program, a nationwide campaign was rolled out which included BABG in-person trainings held at leading transplant centers, educating patients, potential donors, family and friends about living donation. Major transplant centers coast-to-coast have signed on to hold the trainings in the coming year. NKF also

announced a partnership with Medeor Therapeutics to deliver trainings throughout the country. FY18 started with a BABG public service announcement, featuring actor and director Zach Braff and scenes from the movie *Going in Style*, playing in theaters nationwide, reaching over 20 million viewers.

Ten-year-old singing powerhouse and kidney transplant recipient Angelica Hale of television’s *America’s Got Talent* appealed to kids and adults about the importance of living organ donation in a series of five new video PSAs—her first NKF Kid Ambassador assignment. A new PSA series focusing on the African-American community was also developed, featuring America’s first African-American female transplant surgeon Velma Scantlebury-White, MD,

and New York business executive Tracy B. McKibben, who donated a kidney to her mother. (See their stories on page 14.) African Americans are particularly hard-hit by kidney disease, but far less likely to receive a living donor transplant.

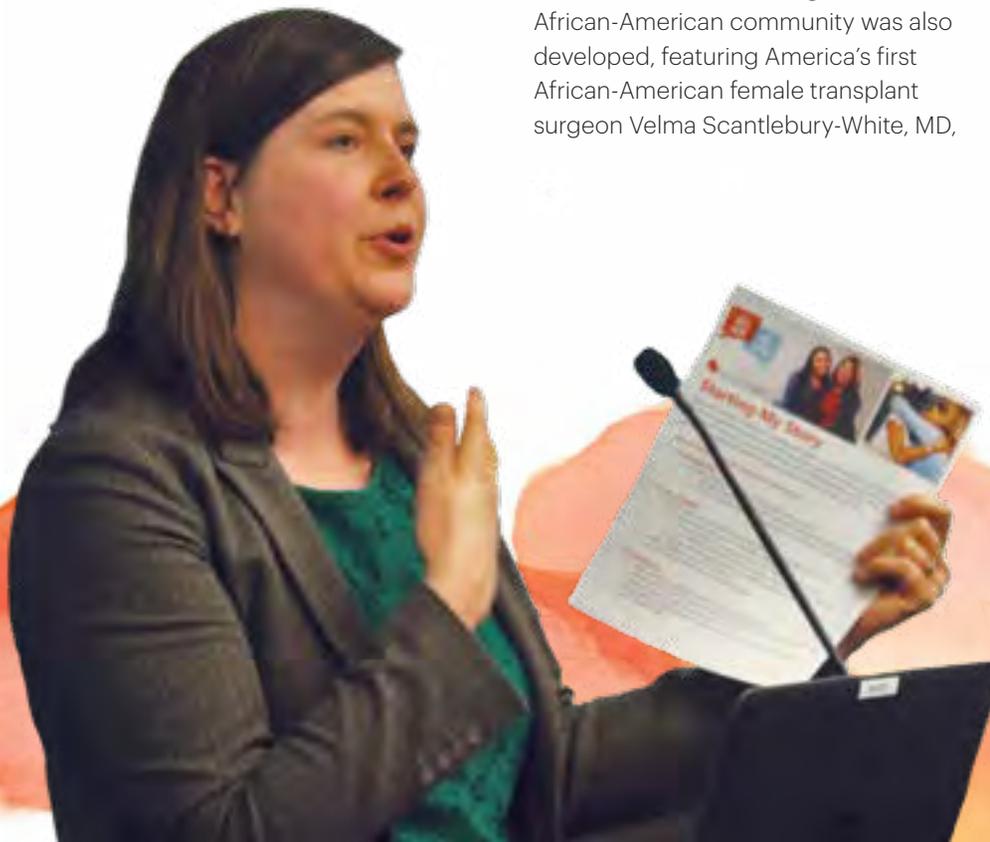
BABG is supported by a comprehensive website featuring video testimonials and materials; a Facebook page and Twitter hashtag [#BigAskBigGive](#); the NKF Cares Help Line; the NKF Peers mentoring program; expanded online promotional and educational print materials; online communities for support and information; and public policy and legislative efforts for increasing living donation. (For the Big Story on THE BIG ASK: THE BIG GIVE see page 18.)

LIVING  
DONATION  
MAKES BETTER  
LIVES POSSIBLE.

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◀ Jennifer Martin, NKF VP of Program Development, getting the word out about BABG.



# NKF: THE SCIENCE

## Major Steps Toward Improving Treatment

Changing kidney health on a national scale and improving the lives of kidney patients starts with “The Science.” NKF was founded to advance research and has invested more than \$100 million to support more than 1,100 researchers investigating the causes and treatments of kidney disease. As part of its continuing legacy of moving the science of kidney disease treatment forward, NKF also hosts major workshops and conferences on key research and treatment issues.

the mortality rate among end-stage renal disease patients in the U.S. has dropped by over

**30** PERCENT

the mortality rate for dialysis patients declined by over

**28** PERCENT

*In FY18, NKF delivered on its mission with several breakthrough developments and major research conferences on kidney healthcare:*

Data from two million patients were gathered and then reviewed at a major workshop to accelerate new clinical trials and treatments for early-stage CKD; a KDOQI home dialysis conference proposed groundbreaking research to measure home dialysis quality and address barriers to home dialysis treatments, which can improve the quality of life and increase independence for patients; patients and care partners joined forces with researchers to identify patient-led national kidney disease research priorities; NKF hosted a major conference to increase utilization of the approximately 3,000 deceased donor kidneys that are underutilized in the U.S. each year; and NKF continues to invest in the future of kidney research through its Young Investigator Awards, supporting high-quality clinical investigations.

*FY18 began with a celebration of one of the original “game changers,” for kidney healthcare, the KDOQI Guidelines...*

### **KDOQI—Celebrating 20 Years**

Twenty years ago, NKF set out to change the standards for treating and caring for dialysis patients and all people affected by CKD. By developing the first comprehensive clinical practice guidelines for kidney disease, known today as the **Kidney Disease Outcomes Quality Initiative (KDOQI)**, NKF created a new classification system and an approach to care used today throughout the world, and in doing so, helped revolutionize the care of patients with kidney disease and improve millions of lives. The guidelines provided the first uniform definition and staging system for kidney disease based on its severity, creating a common language for communication among clinicians, patients and their families, investigators, and policymakers, and a framework for developing a public health approach

to affect care and improve outcomes of CKD. Now 20 years later, NKF has published 18 sets of KDOQI Guidelines, addressing early identification, staging/classification, prevention, and management of kidney disease and related conditions, as well as recommendations for optimization of renal replacement therapy.

“Since the introduction of the NKF-KDOQI Guidelines, the mortality rate among end-stage renal disease patients in the U.S. has dropped by over 30 percent, and the mortality rate for dialysis patients declined by over 28 percent. The KDOQI Guidelines have had a significant impact on clinical practice, research, and public health worldwide and have led to a better understanding of the prevalence of CKD and the best practices for treatment.” ▶ **Kerry Willis, PhD, Chief Scientific Officer, NKF**



▲ Change in Albuminuria and GFR as End Points for Clinical Trials in Early Stages of Chronic Kidney Disease workshop.

### **KDOQI Home Dialysis Conference**

In November 2017, NKF convened the KDOQI Home Dialysis Controversies Conference, which included a multi-stakeholder group of patients, clinicians, researchers, health payers, and policymakers to facilitate the development of research designs that measure home dialysis quality and evaluate interventions to address barriers to maintaining treatment at home. The goal is to remove the barriers to home dialysis so that it becomes a viable choice for anyone on dialysis. The findings from this two-year project will inform the development of a cross-organizational collaboration on a home dialysis quality improvement initiative, headed by KDOQI leadership. *This conference was funded through a Patient-Centered Outcomes Research Institute (PCORI) Eugene Washington PCORI Engagement Award.*

### **Largest Compilation of Kidney Data Ever Collected is Analyzed and Presented at Joint Scientific Workshop**

In March 2018, NKF held the landmark scientific workshop, Change in Albuminuria and GFR as End Points for Clinical Trials in Early Stages of Chronic Kidney Disease, with the Food and Drug Administration and the European Medicines Agency, to accelerate clinical trials which could save and improve patients' lives. (See page 4.)

You can look back at the impact and see the future of KDOQI at: [kidney.org/professionals/guidelines](http://kidney.org/professionals/guidelines)



▲ Nathan Levin, MD  
Founding Co-Chair, KDOQI (1995–2003)



▲ Adeera Levin, MD, FRCPC  
Past KDOQI Co-Chair (2003–2007)

## 2017 Patient-Centered Outcomes Research Stakeholders Conference

Research that includes patients and care partners as active members of the research team has become increasingly important, but before the Spring of 2017, there had been little focus on such methods in kidney disease research. In April 2017, patients with CKD were at the forefront of deciding national research priorities as we led the first-ever **Patient-Centered Outcomes Research (PCOR) Stakeholders' Conference** on kidney disease. The goal of the conference was to transform the way in which the healthcare community viewed patients from passive to active, as engaged partners in the healthcare decision-making process and as key collaborators in research and in policies which directly affect them.

Patients and researchers identified patient-centered research priorities, such as health literacy and communication barriers, patient self-management, preventing and/or delaying kidney disease progression, kidney disease coordinated care, and psychosocial issues. The **top three kidney disease research priorities** identified were: 1) how to engage patients with kidney disease in research, including different communities/populations of patients; 2) health literacy and communication barriers, patient education best practices; and 3) how do we best

educate and partner with patients to understand and self-manage kidney disease?

As part of our commitment to patient-centered outcomes research, NKF is providing funding towards a 2018 Kidney Disease Patient-Centered Research Grant, which will focus on these top kidney disease priorities. The outcomes of this conference will continue to help us further define our role as an organization in facilitating patient involvement in CKD research. *The PCOR Stakeholders' Conference was funded through a Patient-Centered Outcomes Research Institute (PCORI) Eugene Washington PCORI Engagement Award.*

## Patients Share with FDA Experience of Living with C3G, a Rare Kidney Disease

NKF, with participation from the Food and Drug Administration (FDA), conducted an **Externally Led Patient-Focused Drug Development (EL-PFDD) Meeting on Complement 3 Glomerulopathy (C3G)**, a rare form of kidney disease. This was the *first-ever* EL-PFDD meeting focused on kidney disease. The meeting, in August 2017 in Silver Spring, MD, brought together patients, caregivers, physicians who are experts in C3G, and pharma and FDA representatives to learn about the impact of living with this rare disease. This meeting was consistent with NKF's goal of addressing the needs of populations burdened with rare kidney diseases.

C3G typically strikes young patients and their prognosis is poor. While individuals can be diagnosed at any age, C3G disproportionately affects children and young adults. The average age for diagnosis is 21–26 years, and approximately 30–50 percent of C3G patients will progress to end-stage kidney disease within 10 years of diagnosis. Unfortunately for patients with C3G, kidney transplantation is not highly successful, as the disease recurs in more than 50 percent of patients post-transplant, requiring a return to dialysis or a second transplant that is likely to have the same poor outlook as the first. In general, dialysis patients live approximately 15 years less than a person with a successful kidney transplant.

“The goal of NKF’s patient-focused meeting on C3G is to give patients the opportunity to explain to the FDA how this disease affects them personally, so that the agency can understand the disease’s unique burdens and why developing effective medicines is urgently needed. There are currently limited drug therapies available, and no effective, targeted treatment options for the roughly 4,000 Americans living with C3G disease. Working together with the FDA, and patients affected by C3G, our goal is to advance treatment innovations.” ▶ **Joseph Vassalotti, MD, Chief Medical Officer, NKF**

The conference was co-chaired by two leading nephrologists specializing in C3G: Carla Nester, MD, Assistant Professor of Medicine and Pediatrics, University of Iowa, Carver College of Medicine, Iowa City, and Andrew S. Bomback, MD, MPH, Assistant Professor of Medicine, Columbia University Medical Center, New York. NKF has established a C3G Patient Platform, including an online patient community and webinar series. *Lead sponsorship for NKF’s Externally Led Patient-Focused Drug Development Meeting was provided by Achillion Pharmaceuticals. Additional support was provided by Novartis Pharmaceuticals.*



## Advancing Kidney Transplantation

An untapped major source for lifesaving kidney transplants was discussed at the **Consensus Conference to Decrease Kidney Discards**. (See page 19.)

**Research Partially Funded by NKF  
Results in Breakthrough System for  
“Engineering” Kidneys**

A new robotic system to rapidly produce human “mini-organs” to speed up research on regenerative medicine and new drugs has been designed by University of Washington researchers, led by NKF Young Investigator Grant recipient, Benjamin Freedman, PhD, Assistant Professor of Medicine, Division of Nephrology, UW School of Medicine. In 2014 and 2015, Dr. Freedman was the recipient of NKF grants for “Modeling PKD Using Genome Editing in Human iPS Cells,” which eventually led to this breakthrough. Dr. Freedman was researching treatments for polycystic kidney disease (PKD), a devastating condition affecting about six million people in the U.S., which causes cysts to grow in the kidneys, often leading to kidney failure. Dr. Freedman began applying his knowledge to kidney disease because both his grandfather and uncle were on dialysis. Among other applications, the research team at UW is using this new technique to produce organoids with mutations that cause PKD.

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Sources:  
[eurekalert.org/pub\\_releases/2018-05/uowh-rgm051518.php](http://eurekalert.org/pub_releases/2018-05/uowh-rgm051518.php)  
[kidney.org/professionals/Benjamin-Freedman-Engineering-Kidneys](http://kidney.org/professionals/Benjamin-Freedman-Engineering-Kidneys)



▲ NKF research grant recipient Dr. John Lee isolates DNA from cells in urine.

## 2017 Research Grant Recipients

**NKF Young Investigator Awards** assist talented beginning scientists in obtaining funding for their research projects to encourage the best people to enter the field of nephrology. The Young Investigator Awards are for one-year terms. They are based upon careful and balanced peer review by an independent review committee, with an emphasis on the support of high-quality clinical investigation.

### Project: Peritoneal Fluid Microbiome Predictive of Peritonitis

*John Richard Lee, Joan and Sanford I. Weill Medical College of Cornell University; New York, NY*

Peritoneal dialysis (PD) is a widely used dialysis modality around the world and provides life-saving treatment for patients who have kidney failure. Peritonitis is an infection of the peritoneal fluid and unfortunately leads to significant morbidity and mortality in PD patients. Current methods are unable to predict development of peritonitis. We propose to utilize a novel sequencing method called “cell free DNA sequencing” which will provide a comprehensive analysis of the microbiome (i.e., bacteria) in peritoneal fluid. We will study the peritoneal fluid microbiome in PD patients serially over time and determine the microbiome profiles that are predictive of peritonitis. This study will lead to the development of novel diagnostic tests to predict peritonitis and lead to future interventional studies to prevent its devastating complications.



John Richard Lee



Meghan Haley Pearl



Connie Rhee

### Project: AT1R Antibodies in Pediatric Kidney Transplantation

*Meghan Haley Pearl, University of California, Los Angeles; Los Angeles, CA*

Maximizing kidney transplant survival is critical in children, given most will require multiple transplants in their lifetimes. Antibodies in the blood can attack the kidney transplant, causing rejection, injury, or failure. Recently, an antibody called angiotensin II type 1 receptor antibody (AT1R-Ab) has been associated with kidney transplant rejection and failure in adults. Little is known about AT1R-Abs in pediatric kidney transplant recipients (KTRs). We will test blood samples from 200 pediatric KTRs for AT1R-Ab to examine the prevalence and risk factors for development of AT1R-Ab. Furthermore, we will determine if AT1R-Ab is associated with blood vessel injury, decline in renal function, rejection, and transplant failure. This study will enrich our understanding of the effects of AT1R-Abs on transplant outcomes in the vulnerable pediatric population. Our long-term objective is to understand how to incorporate AT1R-Ab testing into kidney transplant monitoring and treatment to improve kidney transplant survival in children.

### Project: Pilot Trial of Thyroid Hormone Replacement in Dialysis

*Connie Rhee, University of California, Irvine; Irvine, CA*

Hypothyroidism, defined by elevated thyrotropin (TSH) levels, is a common endocrine complication of chronic kidney disease that has been associated with impaired quality of life and cardiovascular complications. While levothyroxine is one of the most frequently prescribed medications in dialysis patients, little is known about its efficacy and safety in this population. This study will investigate 1) whether levothyroxine adequately lowers thyrotropin (TSH) levels to therapeutic target ranges, and 2) if thyroid hormone replacement improves quality of life and cardiovascular markers, without leading to wasting (i.e., loss of body mass, fat, and/or muscle mass) in dialysis patients.

### **NKF Southeast Texas Research Grant**

#### **Project: Nephrology Care and Employment After Starting Dialysis**

*Kevin Erickson, Baylor College of  
Medicine; Houston, TX*

Approximately 10 percent of adults in the United States have chronic kidney disease (CKD) and are at risk for developing end-stage renal disease (ESRD), which requires lifelong dialysis treatment or kidney transplantation. There are nearly 500,000 patients with ESRD who receive dialysis in the United States, 20 percent of whom live in California or Texas. Many patients are unable to continue working after they initiate dialysis, which can lead to a reduced sense of well-being, poorer quality of life, and increased state and federal expenditures.

We will examine whether regular kidney specialist (nephrology) care prior to developing ESRD helps patients remain employed after their kidneys fail. We will examine this issue among all patients initiating dialysis in the United States, and among socioeconomically disadvantaged populations with Medicaid insurance in California and Texas. Findings from this study will inform cost-effective/cost-saving policies designed to improve access to pre-ESRD care.



Kevin Erickson



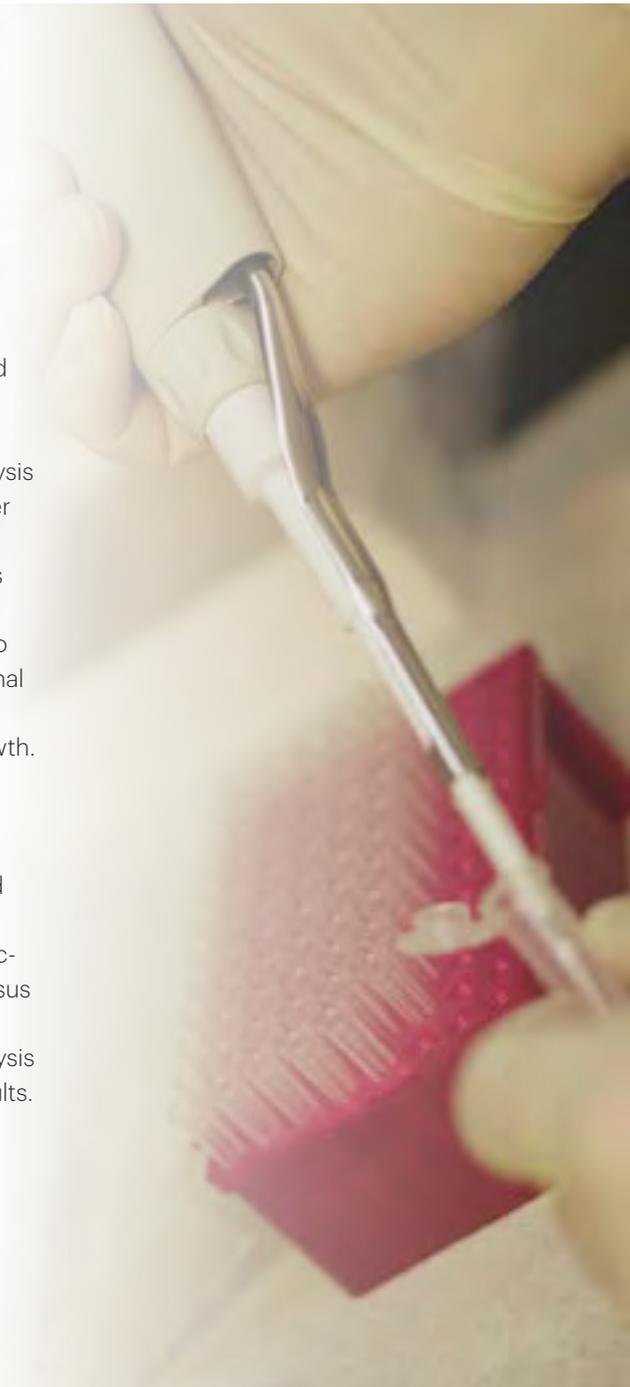
Elaine Ku

### **NKF Satellite Dialysis Clinical Investigator Grant**

#### **Project: Weight Trajectory and Outcomes in Kidney Disease** [grant renewal]

*Elaine Ku, University of California,  
San Francisco; San Francisco, CA*

Obesity amongst chronic hemodialysis patients has been associated with a survival advantage, compared to normal weight, in a phenomenon described as the “obesity paradox.” However, obesity in children on dialysis has not been associated with a lower risk of death, compared to normal weight. One of the potential reasons for these differing observations in adults versus children may be due to delivery of more aggressive nutritional interventions in children with kidney disease to maintain weight and growth. Thus, one reason adults who begin dialysis with a normal weight have a higher risk of death may be due to significant weight loss that occurred prior to needing dialysis. The objectives of this proposal are to: 1) characterize weight trajectory in adults versus children; 2) examine the association between weight change before dialysis and risk of death after dialysis in adults.



# FOCUS ON AFRICAN-AMERICAN COMMUNITIES AND CKD

## **Dr. Velma Scantlebury-White/Tracy B. McKibben**

*They both broke through glass ceilings and racial barriers, now these two odds-breakers want to get the message through to fellow African Americans. Dr. Scantlebury and Tracy B. McKibben are about change—changing the odds that patients and at-risk African Americans are facing with kidney disease.*

Dr. Velma Scantlebury-White, the first Black female transplant surgeon, wants African Americans to stop being number one—at getting kidney disease and being on dialysis. African Americans are three-to-four times more likely to suffer from kidney disease than Caucasians; they have the highest rate of any group.<sup>1</sup> In the face of these daunting statistics, Dr. Scantlebury has performed over two thousand successful transplants in children and adults.

Part of the answer is people simply knowing about kidney disease and its treatment options, as exemplified in the story of New York business executive Tracy B. McKibben, whose mother was on dialysis for three years before Tracy found out that she could donate a kidney to her mom.

These two stand-out women were recently featured in a special 60-second public service announcement, focused on increasing awareness of kidney disease within the African-American community, as part of NKF's THE BIG ASK: THE BIG GIVE platform. The two were also interviewed for an informative, nearly four-minute video available on [kidney.org](http://kidney.org). Both videos have received over 1,200 views on YouTube, and 2,700 on Facebook, and 14 million media impressions and placements nationwide.

“One of the things we battle with is getting African Americans to get checked every year. Because if they were aware of CKD progressing to end-stage kidney disease, there’s that possibility that they could get a living donor and avoid dialysis altogether,” says Dr. Scantlebury-White, Associate Director of the Kidney Transplant Program, Christiana Care Hospital, Newark, DE. “African Americans with kidney disease should know that they don’t have to be on dialysis for the rest of their lives. They should be

encouraged to pursue becoming a candidate for a kidney transplant as early as possible.”

“The impact on our community is greater,” says Tracy B. McKibben, Founder and CEO of MAC Energy Advisors, LLC, a global investment and consulting company. “Having gone to a dialysis center and seeing that the majority of the people there were African American, I was able to immediately see the impact... but I don’t know if many people realize that.”

Born in Barbados, Dr. Velma Scantlebury-White’s family emigrated to the U.S., where she grew up in Brooklyn.<sup>2</sup> The death of her older sister inspired her interest in medicine, which was encouraged by her family. She began in 1972 by working as a volunteer at Kings County Hospital. Branded a “nerd” in high school and told by her guidance counselor to simply get a job, Velma did not give up. She won a four-year scholarship to Long Island University, majoring in biology and pre-med, and graduated with honors in 1977. During her first year of medical school at Columbia University, she decided to become a surgeon. “I was

told that my hands were too small, and I didn’t have what it takes to be a surgeon,” says Dr. Scantlebury. She answered: “Small hands can be better than big hands in surgery, especially when you’re working in small spaces.” She dug in, fought to become a surgeon, and gained her MD in 1981. Dr. Scantlebury became an intern and resident in general surgery at Harlem Hospital in New York for five years, and assisted Dr. Mark Hardy in his research on kidney transplantation.

In 1986, she was awarded a research fellowship at the University of Pittsburgh Medical Center (UPMC) to work with Dr. Thomas E. Starzl, the transplant pioneer, and eventually joined the faculty as a surgery instructor and later an associate professor. She also helped establish a living kidney donor program to increase organ donations among African Americans. In 1989, Dr. Scantlebury married Dr. Harvey White, a professor of public and international affairs and president of the American Society for Public Administration. The couple now has two daughters, Akela and Aisha.

“THE BIG ASK: THE BIG GIVE is really about connecting that recipient that is in need of a kidney transplant with that potential donor who is willing to give.... For many African Americans, they believe that they will need to stay on dialysis for the rest of their life and that is not true. And I think that sets the tone for patients to be discouraged and feel like they’re not a candidate for a kidney transplant.” ▶ **Dr. Velma Scantlebury-White**





"[Organ donation] really didn't change much for me, but it changed so much for the person that I gave the kidney to..."

▶ **Tracy B. McKibben**

Fast forward to today, Dr. Scantlebury is Associate Director of the Kidney Transplant Program, Christiana Care Hospital, where she continues her association with NKF through the Delaware office. She is a big supporter of NKF's THE BIG ASK: THE BIG GIVE platform.

"Once a patient is transplanted they look different, and they feel different. And patients will tell you that it's a remarkable feeling of now being able to urinate on their own after years of being on dialysis...[they] can go back to work, can take trips without having to arrange dialysis, and now can do the kinds of things they always wanted to do."

Dr. Scantlebury's "co-star" in NKF's public service announcement and educational video also has a very compelling story. Originally from Jackson, GA, Tracy B. McKibben always wanted to be a lawyer.<sup>3</sup> Today, she is the head of an international company investing in renewable energy assets in the United States, Europe, and

Africa, coming from a background as a senior-level White House official on economic affairs.

She received a BA in political science, summa cum laude, from West Virginia State, and went on to receive her J.D. from Harvard Law School in 1994. Tracy eventually became a corporate litigator in Washington, DC, where her talent was tapped by the U.S. Department of Commerce. She served as the Director of Executive Secretariat for the Office of the Secretary, and Special Counsel for International Trade and Investments. Then it was on to the National Security Council at the White House, where she served as the Director of European Economic Affairs and EU Relations for the National Security Council and as an Acting Senior Director for European Affairs. In these roles, she advised the President of the United States, the National Security Adviser, Cabinet Secretaries, and senior White House officials on European political, security, economic, and commercial trade issues. She later moved to New York and transitioned

back to the private sector, working at a large multinational investment bank, and then founded her own New York-based company MAC Energy Advisors, LLC in 2010. Additionally, she currently serves on the board of directors of several large corporations, and as a Trustee at New York Power Authority.

Despite her stellar career achievements, for Tracy family comes first. She grew up in a large family of 14 children, and was very close to her parents. When her mother received a diagnosis of kidney failure, she was there. "Kidney disease impacts people's lives in a way that's unimaginable.... My mother was on dialysis for several years. It completely changed the way she lived. We just didn't know that it was an option to be able to donate a kidney.

"I didn't know anyone who'd been on dialysis. I didn't know anyone who'd donated a kidney or an organ. My mother never would have asked...but I wished she had, because we might have moved sooner, so she wouldn't have to do three years of dialysis. My mother was able to have the last nine

years that she had because I donated a kidney to her. I was able to give her a different life."

Tracy is doing all she can to let others know: "...educating ourselves in [the] African-American community about how to be healthier to start with, and then once you have these diseases, what the options are."

On becoming a kidney donor, Tracy says, "I don't know that there's anything better that you can do as a person. The impact that kidney disease has on people's life doesn't have to be the end of the story.

"[Organ donation] really didn't change much for me, but it changed so much for the person that I gave the kidney to.... If you or a loved one is suffering from kidney disease or kidney failure, I highly encourage you to contact your doctor and find out more about living donation—or go to [kidney.org](https://www.kidney.org)!"

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Sources:

1. [https://www.usrds.org/2015/view/img\\_v2\\_01.html#Figure\\_1.14](https://www.usrds.org/2015/view/img_v2_01.html#Figure_1.14)

2. <https://www.encyclopedia.com/education/news-wires-white-papers-and-books/scantlebury-white-velma>  
More information and links to articles about Dr. Scantlebury's distinguished career can be found on that page.

3. *West Virginia STATE Magazine*, Vol. 4, 2016. Available at [https://issuu.com/yumanakada/docs/wvsu\\_state\\_vol4/9](https://issuu.com/yumanakada/docs/wvsu_state_vol4/9)  
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# DECREASING BARRIERS, INCREASING AVAILABILITY

Kidney donation saves lives. 100,000 Americans are waiting for a kidney transplant right now, but only about 19,000 will receive one this year, one-third of which will come from living donors. Living and deceased kidney donors are crucial; 13 people die every day while waiting. A kidney transplant can also improve the quality of life for dialysis patients, freeing them from treatments and extending their lives. NKF knows that kidney patients can't wait.

Leading with *THE BIG ASK: THE BIG GIVE (BABG)* platform of expanded resources, NKF is making an all-out effort to remove barriers to living kidney donation and increase the supply of kidneys available for transplantation.

This includes: expanding BABG trainings for patients and families; building support for the Living Donor Protection Act (H.R. 1270) to prohibit insurance discrimination against living donors; investigating increased use of 3,000 deceased donor kidneys discarded each year; expanding national awareness of the importance of kidney donation; and increasing investments in education and research.

In FY18, BABG went from pilot stage to a full-on rollout, expanding its reach to more potential recipients and more potential donors across the country. The BABG platform of support and resources includes in-person training workshops; the NKF Cares Help Line;

the NKF Peers mentoring program (See page 36.); online support communities; an advocacy campaign to remove barriers to donation; a multi-media public awareness campaign; a Facebook page and Twitter hashtag #BigAskBigGive; expanded online and educational and promotional print materials; and legislative efforts.

**Our First Success Story—**  
*THE BIG ASK: THE BIG GIVE is working!*  
Our first success story comes from a kidney patient, Alan, who found a living kidney donor after using BABG tools and strategies. Alan and his wife Aisha shared his story and need for a donor on Facebook, and a “friend of a friend” stepped forward and donated a kidney to him! Alan and Aisha have shared their “top tips” and strategies for finding a donor through a new video tutorial, which is now available on the BABG website.

“This is a BIG ask—talk about it, get personal, get it out there!” ▶ Aisha

Other real and inspirational stories, as well as continually updated information and resources, can be found on the comprehensive BABG website: [kidney.org/transplantation/livingdonors](https://www.kidney.org/transplantation/livingdonors)

Alan and Aisha ▶

## What else is new with THE BIG ASK: THE BIG GIVE?

NKF Kid Ambassador Angelica Hale of television's *America's Got Talent* turned up the volume and helped spread the word about BABG through interviews, PSAs, and advocacy on Capitol Hill. Angelica appears in [three new video PSAs](#) featuring the message of BABG. (See page 30.) Two other videos, a [60-second PSA](#) and a [four-minute video](#), filmed in FY18 and released during [National Donate Life Month](#) and [National Minority Health Month](#) in April, focus on the African-American community and feature America's first African-American female transplant surgeon [Velma Scantlebury-White, MD](#), as well as New York business executive [Tracy B. McKibben](#), who donated a kidney to her mother. (See their stories on page 14.)

[THE BIG ASK: THE BIG GIVE in-person trainings](#) are open to patients on the transplant waiting list, along with their family members, friends, and potential living donors. The four-hour training workshops are held in partnership with transplant centers, provide education about living donation and transplant in a highly interactive and engaging format, and teach effective strategies for finding a living donor. Early results are promising, with several transplant centers beginning to see more potential living donors stepping forward for testing.

NKF is partnering with transplant centers to expand in-person trainings throughout the country, including the GW Ron & Joy Paul Kidney Center, the Swedish Medical Center, the University of Cincinnati Hospital, and SSM Health St. Clare Hospital. In addition, we have confirmed partnerships with several additional transplant centers to offer in-person trainings in 2018–2019, including a series of five with the University of Pittsburgh Medical Center.

### Increasing Utilization of Kidneys

Not only is NKF working to increase living organ donation, but we're also working to increase the utilization of kidneys from deceased donors, many of which are viable but not used.

In May 2017, NKF convened the [Consensus Conference to Decrease Kidney Discards](#) to explore approaches to increased utilization of the approximately 3,000 deceased donor kidneys discarded in the U.S. each year. With NKF National Board Members and renowned transplant leaders Stephen Pastan, MD, and Matthew Cooper, MD, serving as Co-chairs, the conference brought together 70 key opinion leaders in organ donation and transplantation, including kidney patients and families, transplant surgeons, nephrologists, organ procurement organization leaders, the federal government, and payers to identify reasons that donated kidneys are discarded, as well as practical solutions to increase their use. Leadership

from the Centers for Medicare and Medicaid Services, Health Resources and Services Administration, American Society of Transplant Surgeons, American Society of Transplantation, Association of Organ Procurement Organizations, American Society of Nephrology, and Scientific Registry of Transplant Recipients also participated.

"We've gotten some really good work done on trying to resolve this issue. It's the culmination of about nine months of solid work," said participant and NKF CEO, Kevin Longino. A white paper outlining recommendations for change will be published in a peer-reviewed journal. Participants are also developing detailed action plans for implementation of the recommendations.

### Across the Foundation—Initiatives for Increasing Kidney Donation and Transplantation

*Every area of NKF is committed to removing barriers to living donation and increasing the number of available kidneys. We are engaging NKF's traditional programs, launching new initiatives, as well as partnering with other organizations, to get results for patients on the wait list.*

Under the mantra and hashtag "My Kidneys, My Life" ([#MyKidneysMyLife](#)), NKF Government Advocacy and NKF's Kidney Advocacy Committee (KAC) were out in force at March 2018's Kidney Patient Summit in Washington, DC to support [H.R. 1270, the Living Donor Protection Act](#). [Local NKF advocates](#) are also having success passing

[state-level versions of the LDPA](#). (See page 22.) Living donation is also a major theme promoted by NKF during National Kidney Month and World Kidney Day in March.

[NKF's Transplant Task Force](#) is always working to identify practical tasks to be undertaken to drive kidney donation and transplantation nationally. They have led the development of the Consensus Conference to Decrease Kidney Discards and the BABG platform. [NKF's Council of Professional Living Donor Advocates](#) offers a free email listserv for hospital-based Living Donor Advocates. NKF is also a collaborating partner with Donate Life America and has representation on the DLA Advisory Council to partner on [strategies to increase registration for deceased donation](#).

[Education for kidney healthcare professionals](#) includes a distinct Transplant Professional education program, approved by the American Board for Transplant Certification, at the NKF Spring Clinical Meetings, and SCM courses on new research and caring for kidney transplant patients.

[NKF's Research Grant Program](#) has provided support for researching therapies that could eventually prevent rejection of transplanted organs. NKF is also partnering on PCORI research projects on patient-centered transplant-related subjects. (See page 10.)

# GETTING PEOPLE TALKING

***“It’s like planting a seed, watering it, and watching it grow...”***

*Curtis Warfield received a diagnosis of FSGS (focal segmental glomerulosclerosis) in 2013 and received the “gift of life”—a transplant from his daughter’s college sorority sister—in 2016. He has become a passionate NKF volunteer and advocate for kidney disease awareness and organ donation. He has provided support to patients with end-stage kidney disease on dialysis, as well as those on the transplant waiting list. With a master’s degree in management, Curtis is a senior quality analyst for the State of Indiana. He is active in his church and community, has been married for more than 30 years, and has four children, a daughter-in-law, and one grandchild.*

## **What’s your Kidney Story?**

In 2005, during an annual physical, my doctor ordered a full blood lab workup, due to my family medical history. Upon getting the results, [they found] there was a high amount of protein in my urine. I was sent to a nephrologist who ran more tests and did a biopsy on my kidney. Some scarring damage to some of my kidney filters was detected. I was given steroids for four months, told that my kidney function was back to normal, and released with just a warning that this could come back. Never once did he mention kidney disease.

In 2013, during another physical, my physician noticed some swelling in my legs and ordered full labs. The labs came back with the same results as before: excessive protein in my urine. Then, a different nephrologist told me I had stage three kidney disease. Though my nephrologist tried to slow down the progression of the disease and [had me on] 17 different daily prescriptions, by December 2014, I started peritoneal dialysis. By February, I was placed on the national [kidney transplant waiting] list and told to expect a two- to four-and-a-half-year wait.

My daughter tested as a donor, despite my objections, but doctors said it would not be a good match. Just prior to receiving this news, my daughter was venting to her roommate about the tests and how long they take. When her roommate asked her what was so big about the tests, my daughter replied, “If you think this is so easy why don’t you go and get tested?” Her roommate said okay and went to be tested! On December 18th, 2015, I received a call that “my friend” was a perfect match. On January 8, 2016, my life changed for the best when I received a kidney from a young lady whom I barely knew. I was off work for

six weeks, and my donor only missed two weeks of grad school and later received her master’s degree.

## **Why did you take the extra step from patient to advocate?**

Two major things: When I received a diagnosis of this disease, I felt alone. I really didn’t know anything about CKD, except you go on dialysis, then you die—unless the dice roll in your favor, you luck-up, and get a transplant. My first meeting with [other] people with CKD was very negative. Everyone in that room was angry. So, I want to help people, either by mentoring or through education.

I am so thankful [to] not just one, but two people, young adults [who] were willing to step up and give me a second chance at life. If my donor can give me a kidney that I can’t repay her for, I can give forward to help others.

## **What do you hope to accomplish?**

I want to bring more awareness of kidney disease to: prevent the disease in those who have a chance not to develop it; educate—bring a battle mentality to those who don’t see any hope; increase awareness of organ donation, especially living donation; celebrate those living donor heroes as much as those who have given posthumously; and help break down

myths about CKD, especially in the African-American community and other communities of color.

## **What has been your experience with the NKF Peers program?**

The NKF Peers program has been great! It has been a chance to connect with people and assist them with their situations. To be able to give someone some hope and reassurance that being diagnosed with CKD is not the end of life, to be able to give them a vision toward living a “new normal,” is a humbling experience. I wish I had known of this program when I first started dialysis, because I could have benefited from it.

## **How do you envision the future of kidney health? What’s your ideal?**

I would like to bring kidney health and awareness more to the forefront and not have CKD treated as a secondary disease [instead of just saying] if you have high blood pressures or diabetes, then you can get kidney disease. I believe that our kidneys should be viewed as being as important as the heart.

## **What can a kidney patient do today to improve their life—any tips?**

Stay as physically and mentally active as possible. Get involved as an advocate, at a local, state, or national level.

The more people who are willing to come together as one voice, the bigger that voice can be heard.

**How can the average person better support NKF and kidney health in general—immediately?**

Educate themselves about the importance of kidney health. Be supportive of people with kidney disease and volunteer. Help bring about awareness of kidney disease. Immediately...donate money to NKF and register to be an organ donor. If you are so inclined, take it a step further and get tested to become a living donor.

“The NKF Peers program has been great! It has been a chance to connect with people and assist them with their situations.” ▶ **Curtis Warfield**



# NKF LEGISLATIVE ADVOCACY:

## Making a National Impact

NKF has always recognized the transformative potential of legislation for millions of lives—especially those of kidney patients. In the 1960s, NKF was instrumental in securing the first federal funds for kidney programs. In 1968, NKF helped draft and pass the 1968 Uniform Anatomical Gift Act—and distributed tens of millions of kidney donor cards. The milestone ESRD benefit within Medicare, advocated by NKF and established in 1972, still provides healthcare for nearly all Americans with kidney failure. Today, we continue to change the healthcare culture and patients' lives by advancing legislation and public policy on behalf of people with kidney disease.

### NKF Legislative Advocacy in FY18

NKF continued to build support for the [Living Donor Protection Act \(H.R. 1270\)](#), introduced by Representatives Jerrold Nadler (D-NY) and Jaime Herrera Beutler (R-WA), to prohibit discrimination in the issuing or pricing of life, disability, and long-term care insurance for living organ donors. The bill also clarifies that living donors may use the Family and Medical Leave Act (FMLA) when recuperating from donor surgery. Meetings by our patient advocates on Capitol Hill and in their home states have resulted in nearly twice as many co-sponsors compared to that of the previous Congress, and we are optimistic H.R. 1270 could be enacted in 2018.

Another top legislative priority, [H.R. 3867](#), introduced by Representatives Markwayne Mullin (R-OK), George Holding (R-NC), Linda Sánchez (D-CA),

and G.K. Butterfield (D-NC), would establish a voluntary [Medicare pilot program](#) to help improve care and outcomes for CKD patients. The legislation seeks to demonstrate that early detection of CKD, combined with effective and coordinated care by a multidisciplinary team that engages patients in the decision-making process, can improve clinical results and lower healthcare spending. Medicare spends over \$100 billion annually on CKD, two-thirds of which is for patients who do not have kidney failure.

NKF has been busy at the state level as well. We led an effort in [Pennsylvania](#) that [restored nearly all the funding](#) Governor Wolf had proposed to cut from the [Chronic Renal Disease Program \(CRDP\)](#). More than 1,750 letters, tweets, and calls were received by the state legislature and

Governor, and staff members from our Pennsylvania offices met with state officials as well. The CRDP assists lower income kidney patients with prescription drug expenses, copays, transportation to dialysis, and other needs.

In [Idaho](#), NKF worked to enact [S. 1302](#) The Living Organ Donor Protection Act, [to protect living organ donors](#) from discrimination in life, disability, and long-term care insurance. The legislation, signed by Governor Otter during a small ceremony at which NKF advocates attended, is the *first of its kind* that has been enacted for living organ donors. (See page 56.)

### #MyKidneysMyLife Inspiring Action for Kidney Disease

Nearly 100 advocates from kidney organizations around the country, joined by first-ever NKF Kid Ambassador Angelica Hale (See page 28.),

converged on Capitol Hill to meet with their lawmakers to inspire action on kidney disease at the [5th Annual Kidney Patient Summit](#), March 5–6, 2018. Led by NKF and carrying the mantra “My Kidneys, My Life,” the event brought together members of the NKF Kidney Advocacy Committee and advocates from the Alport Syndrome Foundation, American Association of Kidney Patients, PKD Foundation, and NephCure Kidney International, who used their collective experiences to champion legislative priorities.

Advocates representing nearly all 50 states shared their stories and urged Members of Congress to support H.R. 3867 and H.R. 1270. This Summit's newest kidney advocate, transplant recipient Angelica Hale, supported legislative priorities: Angelica was available for media interviews and was featured in a Facebook Live Q&A

session with Members of Congress Jaime Herrera Beutler (R-WA) and Bill Posey (R-FL).

The summit culminated with the annual NKF Congressional Awards Reception, chaired by former Wisconsin Governor Tommy Thompson, and honored selected Members of Congress for their commitment to fighting kidney disease: Representatives G.K. Butterfield (D-NC), George Holding (R-NC), Markwayne

Mullin (R-OK), and Linda Sánchez (D-CA). The reception, with nearly 150 advocates and congressional staff in attendance, featured a powerhouse performance by Angelica, who not only helped present awards, but received one herself for her outstanding work! A video covering the entire summit can be seen on NKF's YouTube Channel and for more on media coverage of the Summit, see page 31.

▼ (L-R) Lizbeth Alvarez, staff member for Sen. Kamala Devi Harris (D-CA), and Kidney Advocates: Lenora Cross, Grant Bonebrake, Derek Forfang, Lisa Bonebrake, Doris Lew.



▲ NKF CEO Kevin Longino, Rep. Markwayne Mullin, Angelica Hale, and Gov. Tommy Thompson.





KIDNEY PATIENT SUMMIT

KIDNEY PATIENT SUMMIT

KIDNEY PATIENT SUMMIT

### Kidney Advocacy Committee

As a leader in patient engagement, NKF ensures that patients are involved in all aspects of research, development, policy, education, and care. We aim to make patient involvement the norm in the entire healthcare system. These efforts are led by the **NKF Kidney Advocacy Committee (KAC)**, a growing group of nearly 200 patient liaisons who are involved in all NKF programs and with external partners. Using their personal experiences and expertise, KAC members also provide valuable insight into development of our **THE BIG ASK: THE BIG GIVE** in-person trainings. KAC advocates are especially active on NKF's Public Policy Committee and in multiple external partnerships, such as: workgroups with the National Health Council (NHC) to improve patient engagement in drug development; research proposals for the Department of Defense (DoD), which helps direct how grant funding is allocated for CKD research; technical expert panels (TEPs) with the Centers for Medicare and Medicaid Services (CMS); and the National Kidney Disease Education Program's (NKDEP)

development of a new LOINC code through the "Chronic Kidney Disease Management Personal Goals Panel," which will make it possible for healthcare providers to see, ask questions, and record responses about kidney patients' health and personal goals in their electronic health records.

### New Medicare Incentives for Early CKD Detection and Treatment

NKF's Public Policy team is working with Congress and health agencies on creating healthcare industry incentives to prevent and treat CKD, and improve quality of care. In addition, the NKF team recommended to the Centers for Medicare and Medicaid Services a new Medicare payment model to improve earlier detection of CKD and improve treatment of patients throughout their CKD journey. In 2018, CMS adopted NKF's recommendations to include CKD stage 3 in changes to the risk adjustment model for Medicare Advantage plans. This encourages the plans to work with healthcare clinicians to improve earlier diagnosis and treatment of the disease.

### NKF's CKDintercept

*NKF's CKDintercept (CKDI) platform is a multi-year initiative that aims to elevate CKD diagnosis and management to the front lines of preventative health in the U.S. health system. CKDintercept employs a diverse, ever-broadening strategy of activities involving primary care practitioners (PCPs), managed care, laboratories, educational institutions, government agencies, and the patients themselves. (See page 5.)*

**CKDI Payer Roundtable**—Payers face significant obstacles to improving CKD care across the continuum of the disease. NKF convened a roundtable

discussion with the senior medical leadership of nine large health insurance payers. This meeting highlighted the efficacy of early CKD intervention, and discussed the alternative payment model developed by NKF.

**CKDI Quality Measure Development**—NKF has developed a suite of quality measures to improve CKD recognition and management in primary care. NKF is testing measures to limit the use of drugs that damage the kidneys and ensure that people with CKD are referred to nephrology in a timely manner.

### Grassroots Advocacy!

In FY18, local NKF advocates secured

**13** Living Kidney Donor Day proclamations in their states.



# THIS CONGRESSMAN'S STATEMENT: "YOU ARE NOT ALONE"

## **Rep. Posey is at Work for His Kidney Constituents**

On and off Capitol Hill, in his role as a Member of Congress or as a member of the public, [Representative Bill Posey](#) (R-FL) is a strong and steady advocate for kidney health and kidney patients. Rep. Posey is also a passionate supporter of NKF at both the national and local levels. He serves as the Honorary Chair of NKF of Florida's Footprints in the Sand Kidney Walk, held in Cocoa Beach every May, where he participates with hundreds of fellow walkers.

The 2018 Footprints Walk took place during Mother's Day weekend and Rep. Posey presented donor mothers with a special proclamation, a Congressional Certificate of Recognition to honor the mothers of organ donors. Rep. Posey also submitted a Congressional Record statement to celebrate these donor moms and the ultimate gift of life provided by their children.

Rep. Posey first learned about CKD as a member of the Florida state legislature when NKF staff and patients visited lawmakers at their annual State Kidney Day. He built a particularly strong relationship with one of our Florida Affiliate's long-time staff members, three-time kidney transplant recipient

Richard Salick who, with Co-chair Bill Hahn, founded the Footprints in the Sand Kidney Walk.

Prior to his kidney failure diagnosis at age 23, Rich was a national champion surfer and karate expert who, by all appearances, was in perfect health. Following his first transplant, told his surfing days had ended, Rich refused to back down and returned to competitive surfing. Rich set an example of how to meet serious health challenges, no matter what the circumstances, and did everything possible to assist kidney patients, including founding the annual NKF Pro-Am Surf Festival in Cocoa Beach 30 years ago, raising millions of dollars.

When Rich passed on in July 2012, his close friends Rep. Posey and Bill Hahn found a special way to commemorate his life and work. On December 16, 2014, President Obama signed into law H.R. 451, designating the Brevard Avenue Post Office in Cocoa Beach, FL, as the "Richard K. Salick Post Office" to honor his tireless efforts for kidney patients. And Rep. Posey continues to participate in every Footprints Kidney Walk with his wife, Katie.

Rep. Posey's compassion and concern for kidney patients is evidenced by his consistent support of NKF's legislative priorities, including the Living Donor Protection Act (H.R. 1270) and legislation to improve early detection and treatment of CKD (H.R. 3867). The Congressman, along with Rep. Jaime Herrera Beutler (R-WA), participated in a Facebook Live interview with NKF Kid Ambassador Angelica Hale during our 2018 Kidney Patient Summit in Washington, DC. The gentle chemistry between the veteran Congressman and our brave, new 10-year-old Kid Ambassador made for a very moving interview. "You're a good Ambassador, Angelica," said Rep. Posey, "The more people you meet, the more people are going to be tuned in!"

Rep. Posey described how his friend Rich introduced him to another young kidney transplant recipient like his interviewer—12-year-old Jessica Harder, whose transplanted kidney was dying because she could not afford the immunosuppressive drugs. The state had paid for Jessica's transplant, but would not pay for her immunosuppressive drugs, and she wound up losing the kidney. Fortunately, Jessica

received another kidney, saving her life, but this situation did not make sense to Rep. Posey, and he got behind passing legislation in Florida to cover the necessary drugs—for everyone. (Angelica pointed out that she started on immunosuppressive medications around the same time and gave a heartfelt thanks to Rep. Posey for his successful efforts.) This deepened his involvement and understanding of the issues facing kidney patients: "Until we find a 100 percent cure, we're going to do everything we can for awareness and treatment."

Through his current support of H.R. 1270 and H.R. 3867, participation in the Footprints Kidney Walk, and accessibility to patients and families, Rep. Posey continues to rally behind the cause of kidney health.

Congressman Posey is a true champion for NKF and kidney patients everywhere!



Congressman Posey presented a Congressional Certificate of Recognition to honor the mothers of organ donors at the The Footprints in the Sand Kidney Walk on Mother's Day weekend.

"Until we find a 100 percent cure, we're going to do everything we can for awareness and treatment."  
▶ Representative Bill Posey



# WHY WE LOVE ANGELICA

## Courage with a Great, Big Smile

Sometimes that smile seems bigger than she is! And her singing voice? Forget about it—people stop and just listen. It's astonishing. She was a 2017 show-stopper on *America's Got Talent*, the youngest runner-up in the show's history. The audience was stunned by the big sound coming from such a small person. Yet, what's most amazing about an already amazing person isn't her smile or her voice, it's her story.

In 2012, when Angelica Hale was four, she contracted severe bacterial pneumonia, which caused her kidneys to fail, among other major health issues. After spending 80 days in Children's Healthcare of Atlanta hospital and a year on dialysis, Angelica received a life-saving kidney transplant from her matching donor—her mother, Eva. Today, mother and daughter are healthy.

"My mom is my superhero. She brought me and my dreams of singing back to life," says Angelica.

The Atlanta native had been singing since she was two and began taking professional vocal lessons when she was five. Her transplant story made her a natural partner for NKF, and in November 2017, Angelica was appointed NKF's first Kid Ambassador.

Her two-part mission: to spread the word about the importance of kidney health through the Heart Your Kidneys awareness campaign; and to appeal to kids and adults about the importance of living organ donation, as explained in THE BIG ASK: THE BIG GIVE. (See pages 7, 18.)

"I am honored, because I know the situation that everyone is in....I am excited to spread the word, because there are tons of people who are in worse situations than me. I want to help everyone," says Angelica.

Angelica's first NKF assignment was to appear in a series of new public service ads filmed at the legendary Village Studios in Los Angeles. (See the videos at [kidney.org/livingdonation](http://kidney.org/livingdonation))

It was the first time people would hear her distinctive voice letting people know about the importance of kidney health and the urgent need for living donors. She did a behind-the-scenes Facebook Live interview, where she said, "You only need one [kidney] to be a healthy person, so you can give one away to someone who needs it. It's a win-win."

Leading up to New York's Thanksgiving Day Parade, Angelica recorded an interview for NYC's famed 1010 WINS/

CBS Radio, which was broadcast during morning drive time, and was interviewed for Radio.com, both highlighting her new NKF role.

In March, it was on to Washington, DC, where Ambassador Angelica's next mission was a big one. She joined nearly 100 advocates from kidney organizations around the country on Capitol Hill for the 5th Annual Kidney Patient Summit. Advocates, including Angelica and her parents, shared their stories with Members of Congress to support H.R. 3867 to improve early CKD detection and the care of patients, and H.R. 1270, the Living Donor Protection Act. (See page 22.)

Angelica put in a full-day's work on both days of the summit. She was interviewed by the NBC, ABC, and FOX television affiliates in DC, and spoke out on the importance of passing these bills, how living donation saves lives, and how everybody should pay more attention to their kidney health.

Angelica even got to turn the tables and became a reporter herself! On Facebook Live she hosted a charming and informative Q&A with Members of Congress Jaime Herrera Beutler (R-WA; featured in last year's Annual

Report) and Bill Posey (R-FL; profiled on page 26). The interview received more than 22K views.

At the summit's end, Angelica was the main event at a celebratory gala attended by Members of Congress and kidney advocates. She performed a stellar rendition of "The Greatest Love of All" during the evening NKF Congressional Awards Reception, chaired by former Secretary of Health and Human Services and Wisconsin Governor Tommy Thompson. This was also captured on Facebook Live and received 70K views. Media outreach for the Summit, including Angelica's work, reached 18 million viewers.

"Kids and adults look up to Angelica," said Kevin Longino, NKF CEO and fellow kidney transplant recipient. "I am also inspired by her and the stories of all of the advocates attending this year's Kidney Patient Summit."

Angelica is out there at work now, most recently as of this writing interviewing with Kathy Lee and Hoda on the *Today* show—and throwing in an outstanding singing performance of "I'll Be There"—proudly telling the world about kidney health and her role as NKF's Kid Ambassador!

"I am here in this world for a reason. I have been given so much love and hope. I want to help. I want to thank all the doctors and the nurses who work so hard. Be a donor, because it is so needed. I am so happy to be the Kid Ambassador!" ▶ **Angelica Hale**



# PUBLIC AWARENESS, MARKETING, AND COMMUNICATIONS

## Getting the Message Through

Whether it's public awareness about kidney health or the need for living donors, letting scientists know about breakthrough research, or rallying support for a bill in Washington, DC, marketing and communication are essential parts of our mission. The job of the NKF Marketing and Communications Department is to connect the people we serve to what we do, and increase the national reach of our mission and message of kidney health.

### THE BIG ASK: THE BIG GIVE

**THE BIG ASK: THE BIG GIVE** (BABG) platform is designed to increase kidney transplantation with training and tools that help patients and families find a living donor. Building upon last year's launch, the public awareness portion of the BABG platform continues to grow and develop. In FY18, THE BIG ASK: THE BIG GIVE "went Hollywood" with a public service announcement (PSA) featuring actor and director Zach Braff, and scenes from the movie *Going in Style*. The PSA played in theaters nationwide, reaching **more than 20 million viewers**. This set the stage for the nationwide launch of a major NKF initiative, BABG in-person trainings, developed by the Education and Programs Department and held at

transplant centers across the country. Then came 10-year-old singing powerhouse, kidney transplant recipient, and *America's Got Talent* contestant, **Angelica Hale**. (See page 28.) As the first-ever NKF Kid Ambassador, Angelica's first series of PSAs, press and Facebook Live in support of BABG launched in October and November 2017, and focused on her own story as a kidney recipient. This **campaign reached 48.7 million people and brought BABG directly to kids and families** facing the same challenges.

Reaching communities at risk was the next focus of THE BIG ASK: THE BIG GIVE public awareness campaign. A new, nearly four-minute, long-form video and a 60-second PSA, both focusing on the African-American

community, were produced by NKF, featuring America's first African-American female transplant surgeon **Velma Scantlebury-White, MD**, and a leading New York business executive **Tracy B. McKibben**, who donated a kidney to her mother. (See their stories on page 14.) The videos, released during National Donate Life Month and National Minority Health Month in April 2018, have received **more than 14 million media impressions** so far. New BABG-branded materials and print ads also supported the campaign. **The BABG public awareness campaign has reached well over 100 million media impressions to date.** (See pages 7, 18 for more on THE BIG ASK: THE BIG GIVE.)

THE BIG ASK: THE BIG GIVE public awareness campaign has reached well over

**100** MILLION  
media impressions  
to date.

Angelica's BABG campaign reached

**48.7** MILLION  
people and brought  
BABG directly to kids  
and families.

## “Heart Your Kidneys” Wakes Up the Country During National Kidney Month and World Kidney Day!

A major traditional and social media campaign ran throughout National Kidney Month, reaching

**170** MILLION

**Heart Your Kidneys** was once again the theme of NKF’s campaign for another successful **National Kidney Month and World Kidney Day** in March 2018! From Angelica Hale taking Capitol Hill by storm, to landmarks across the nation “going orange” for kidney disease, we were able to make both local and national impacts in the news and in communities. A major traditional and social media campaign ran throughout the month, and included nationwide coverage with broadcast PSAs, social media campaigns, and print articles **reaching 170 million**. And on the evening of WKD, iconic buildings and landmarks throughout the U.S. turned orange—the signature color for kidney disease, thanks to NKF’s National and local offices. (See page 57.)

In one of the big highlights of National Kidney Month, nearly 100 advocates from kidney organizations around the country—joined by NKF Kid Ambassador Angelica Hale—converged on Capitol Hill to meet

with their lawmakers to inspire action on kidney disease at the **5th Annual Kidney Patient Summit** in Washington, DC on March 5–6. (See page 22.) The summit gained more public attention at the outset this year with the help of Angelica, who took her new Ambassador role very seriously. She was interviewed by NBC, ABC, and FOX television affiliates in DC. She also led a Facebook Live Q&A with Members of Congress Jaime Herrera Beutler (R-WA) and Bill Posey (R-FL). Angelica later performed during the evening NKF Congressional Awards Reception, which was captured on FB Live.

Angelica’s Facebook Live Q&A with Members of Congress Jaime Herrera Beutler (R-WA) and Bill Posey (R-FL). ▶



## Connecting NKF to the World— and the World with Kidney Health

*Making NKF's work more accessible means making it more useful—in improving and saving lives. The Marketing and Communications Department uses online video, as well as social and traditional media, to reach our audience of patients, the public, and healthcare professionals.*

In FY18, promotion of research, healthcare initiatives, and professional education began with NKF celebrating the **20th Anniversary of the KDOQI Guidelines**. (See page 8.) NKF Scientific Activities and Marketing and Communications Departments developed a **video** on the pivotal

importance of the guidelines to kidney patient care, including interviews with prominent nephrologists, many of whom worked on the original DOQI and KDOQI Guidelines.

In February 2018, NKF launched the game-changing **CKDI Laboratory Engagement Plan**, collaborating with the American Society for Clinical Pathology (ASCP), the nation's leading laboratories and clinical laboratory societies to change the way CKD is detected and treated. (See page 5.) Marketing and Communications, collaborating with ASCP and laboratory partners, provided creative assets, and

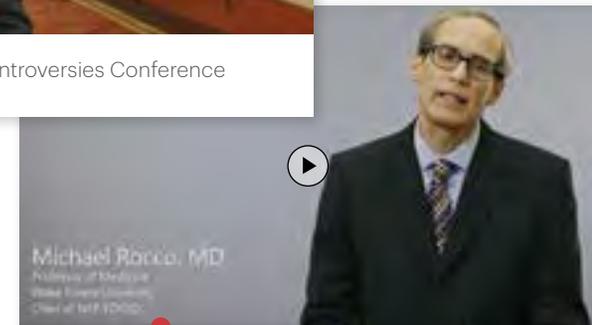
led the public launch activities. Initial media outreach was **nearly 18 million impressions**.

Accelerating new clinical trials and treatments for kidney disease was the focus of **a new video series which featured the world's leading nephrologists**, researchers, and officials from the Food and Drug Administration (FDA) and European Medicines Agency (EMA). The series explained to NKF supporters and the public the significance of the joint scientific workshop **Change in Albuminuria and GFR as End Points for Clinical Trials in Early Stages of Chronic Kidney Disease** and its potential impact on kidney patients throughout the world. (See page 4.)

Initial media impressions from the scientific workshop launch and videos reached **16.6 million**. The **NKF KDOQI Home Dialysis Controversies Conference**, focusing on the need for improved home dialysis, was profiled in an NKF video highlighting the importance of this project for patients and families. (See page 9.) And a **new series of social videos**, designed in-house specifically for **patient education**, was **launched to address the daily issues kidney patients face**: *Thirst Tips for Dialysis Patients* and *5 Foods to Avoid or Steer Clear From for Kidney Health*. This successful social series will continue to address more top-of-mind topics for kidney patients.



KDOQI Home Dialysis Controversies Conference



KDOQI 20th Anniversary

## NKF's Digital Transformation

NKF is continuing to digitize more of our existing offerings, and we are producing more digital content than ever, including Facebook Live events, social videos, and website content. NKF is also revising our national email marketing to target readers' individual interests, guided by a "Connection to Kidney Disease," and have added more than 25K new connections since we began our efforts. We have recently completed a redesign of our email preference center, allowing users to opt-in and opt-out of various topics, based on interest. In addition, we are getting ready for a complete website redesign and reworking the information architecture on [kidney.org](http://kidney.org) to improve user experience and searchability. NKF was an early adopter of Facebook's new Fundraiser tools bringing in \$502,811 in FY18, expanding our individual giving outreach.

## Raising Funds and Public Consciousness

Marketing and Communications also collaborates with the Development Department on amplifying NKF's existing [fundraising programs](#) and finding new sources of support. Bryson DeChambeau rejoined NKF [Konica Minolta Golf Classic](#) with his Birdie Challenge during National Donate Life Month, raising \$15,000. (See page 43.) The [Birdie Challenge](#) is a social media and web-based event ([#NKFBirdieChallenge](#)) in which DeChambeau pledges to donate \$250 per birdie and \$500 per eagle that he makes on the PGA Tour, and challenges his followers to make pledges. The campaign was promoted using traditional and social media with audience reach exceeding [47 million](#). For [Team Kidney's Birthday Campaign](#), participants pledged and donated their next birthday to NKF, in lieu of presents. [#GivingTuesday](#) is a global day of giving fueled by the power of social media and collaboration. Marketing and Communications along with the Development team partnered on a comprehensive Giving Tuesday campaign, consisting of social ads, messaging, Facebook Live events, and a [\\$100,000 matched giving challenge](#).

Marketing and Communications also updated [media materials](#) and produced a new sponsor video of the [NKF Kidney Walk](#) partnership with Fresenius Medical Care North America. (See page 43.) NKF field staff across the country now have an [updated suite of sales tools](#) to help them articulate our brand platform, including materials for the [Team Kidney](#) custom fundraising platform and [NKF social media events](#). A new forum, [NKF Media Matters](#), shares tips for media placement success.



Your [#GivingTuesday](#) gift unlocks twice the support for kidney patients.

[DONATE NOW](#)

[#GivingTuesday](#)

A comprehensive Giving Tuesday campaign, consisted of social ads, messaging, Facebook Live events, and a \$100,000 matched giving challenge.



The Birdie Challenge audience reach exceeded

**47** MILLION

Bryson DeChambeau ▶

# PARENTS X 3

## Two Parents Give One Child Life—Three Times It's a Family Thing...

By Traci A. Kozak-Krist, NKF Kidney Advocacy Committee Advocate, Living Donor Council (LDC) Executive Committee member

Traci A. Kozak-Krist is a living donor. Her husband Matt is a living donor. Their son, Tanner, who was born with malformed kidneys, is the recipient. Traci and her family support kidney patients through advocacy, an appearance in a public awareness video, and forming a Kidney Walk team. Traci currently teaches second and third grade at Letchworth Central School District in Gainesville, NY.

All parents worry about their kids, but having a child with a transplant takes it to a whole new level. Here, Traci tells of her family's journey in her own words...

*My husband and I never stop worrying. We worry about everything. Did he drink enough today? Is his diet balanced? Do any classmates have a contagious infection? Did he take a nap? Is he getting sick? Is he moody? Do you think this is a sign of rejection? These questions and concerns never end. They are always in the back of our minds, waiting for an opportunity to become our reality.*

*Our family has been living with CKD since July 1, 2001: the day our first and only child, Tanner, was born. He was born seven weeks prematurely with underdeveloped kidneys. His CKD is not related to any disease or syndrome. By the time Tanner was five years old, his kidney function had decreased to a point that he needed a transplant. Over the next nine months, we prepared for Tanner's transplant. And on April 11, 2007, Tanner's father donated his kidney.*

*We developed the daily habits and routines [which] included recording fluid intake and output, setting alarms when it was time for Tanner to take medications, making sure hands were washed or sanitized randomly throughout the day, and covering Tanner in sunscreen whenever he was going to be outside. As the days and weeks went by after the transplant, we never wavered with our daily routine: Set alarms and take meds at 8:00am and 9:00am, then again at 8:00pm and 9:00pm. If Tanner was with family, friends, or sitters we would call or send*

*a text to make sure the medicines were taken. This was a challenging time because my husband and I had to believe that when Tanner was with other people, he would get meds on time, drink enough fluid, not be exposed to contagious infections, and most importantly, wear his kidney shield [a special padded belt to protect the transplanted kidney] all of the time.*

*My husband and I knew that having a child with a transplanted kidney would take a lot of time, energy, and communication. What we weren't prepared for were some of the dips and bumps in the rollercoaster of transplant life. Just when we thought things were going well, Tanner would have a case of rejection and we'd have to spend 5-10 days in the hospital getting treatments. Over the years, no matter how many rejection episodes for which Tanner was treated, my husband and I always have the same fears and emotions. Today, it is not unusual for us to cry as a family. If one of us starts crying, the other will be soon thereafter.*

*Another aspect of post-transplant life for which we weren't truly prepared... are long-lasting side-effects because of the steroid treatments given to stop rejection. For the past three years, Tanner has had to test his blood glucose levels and take insulin for varying lengths of time after he is treated for rejection. This has likely been the biggest challenge we've had as a family. Tanner is considered to have diabetes. And this angers him. Tanner flat-out denies that he has a diabetes problem. He is adamant that it's a short-term problem and will go away. Unfortunately, that may not be the case. Long-term care may be required to aid his pancreas in production of insulin. Only time will tell. During these teenage years, we try to continue to be a typical family. But it's hard when the concerns, issues, or routines are too real. They keep us vigilant; we remain hopeful for Tanner's future.*

The Kozak-Krist family's story can be shared from: [nkfadvocacy.wordpress.com/2018/03/14/a-moms-perspective/](https://nkfadvocacy.wordpress.com/2018/03/14/a-moms-perspective/)

“My husband and I knew that having a child with a transplanted kidney would take a lot of time, energy, and communication. What we weren’t prepared for were some of the dips and bumps in the rollercoaster of transplant life.”

▶ **Traci A. Kozak-Krist**

Tanner and Traci ▶



# PATIENTS & PROFESSIONALS:

## **Both Sides of the Kidney Healthcare Equation**

The most effective way to achieve the best healthcare outcomes for kidney patients is through education and support of both the patients themselves and their healthcare teams. NKF has coordinated its resources to have a positive impact on patients' quality of life and care by educating all stakeholders in the healthcare setting.

## Patient Support

### **NEW! Online Communities**

HealthUnlocked and NKF announced a new collaboration and four new online communities that provide vital help, support, and information to people with, affected by, or at risk for kidney disease. The online communities provide peer-to-peer support to anyone affected by kidney disease, along with access to information and resources, while assisting NKF in identifying any HealthUnlocked users at risk for developing kidney disease. The collaboration spans both prevention and support for those affected. NKF has four different communities on HealthUnlocked that include kidney disease, dialysis, living donation, and transplant. Each of these online communities will provide a free resource, open to people with the condition or those looking for prevention advice, no matter what their stage of CKD or type of treatment

they are on. Our fast-growing communities are already supporting thousands of people!  
[kidney.org/online-communities](http://kidney.org/online-communities)

### **NKF Cares—People, Not “Prompts”**

When a kidney patient or caregiver calls toll-free NKF Cares (1.855.NKF.CARES (1.855.653.2273) during business hours, a Cares staffer answers directly. NKF Cares Help Line provides a supportive ear, as well as accurate, updated information and resources when patients and families need it most. Our trained staff provide support, education, and guidance to over 15,000 people per year via email, mail, and telephone in both English and Spanish.

### **NKF Peers—Talking to Someone Who’s “Been There”**

Trained mentors provide support to their peers facing dialysis, transplant, or those considering becoming

living donors through our NKF Peers program. Dealing with kidney failure and facing difficult decisions about treatment options can leave people feeling overwhelmed. Talking to someone who’s “been there,” in a safe, anonymous environment, can be invaluable. NKF Peers’ success is apparent: **97 percent would recommend NKF Peers to someone in a similar situation.**

The NKF Peers program is also partnering with the Patient-Centered Outcomes Research Institute (PCORI) on research projects:

- **Putting Patients at the Center of Kidney Care Transitions**, with Duke University and Geisinger Health Systems, is about developing The Kidney Care Transitions program to link patients with key resources and assist with health choices, including peer support by patient mentors trained by NKF.

- **Enhancing the Cardiovascular Safety of Hemodialysis Care**, with the University of Michigan: NKF is developing and implementing peer mentoring that couples our traditional peer support model with educational modules to reduce cardiovascular events.

### **Community-Based Prevention Programs**

NKF provides community-based programs to prevent and diagnose kidney disease as early as possible. Our KEEP Healthy program offers free kidney health checks to identify risks for kidney disease—people with high blood pressure, diabetes, or a family history of kidney failure. We also provide ongoing education to the public about kidneys, kidney disease and those at risk. (See page 30 for more awareness initiatives.)



## From living donor mentees:

“The genuine caring and willingness of the donor callers to answer any and all of my queries, and their individual personalities. I felt comfortable in talking to each of the women, who had different stories of their experience.”

“I was able to speak specifically with a female in my age group; she was able to address my age issue questions, relative to her donation experience.”

“They set everything up for me to my schedule. All I had to do is pick up the phone.”

“I like the opportunity to talk with someone who has been through the experience, but is not a medical professional.”

## Patient and Professional Education

### Kidney Learning Solutions (KLS)

In FY18, NKF's KLS expanded its educational offerings for healthcare professionals, patients, and care partners. As a way of organizing our many **patient offerings**, KLS has developed **comprehensive microsites**, offering more structured online learning platforms. Another new, successful way to reach specific audiences is **Facebook Live**.

Recent FB Live productions include: high potassium, kidney cancer, and the interplay between cardiovascular disease, diabetes, and CKD.

The other cornerstone of KLS's programming is **education for health-care professionals**. In FY18, KLS developed online **"Master Classes"** on high potassium and Fabry disease, as well as a clinical **smartphone app**,

**"CKD Care: An Interactive Guide for Clinicians,"** which offers strategies to diagnose and manage CKD and acute kidney injury. FY18 also saw the development of **new online CME/CE programs** on hepatitis C, mineral and bone disease, anemia, high potassium, CVD, and hyperuricemia/gout. For the first time, KLS developed a novel **"Flipped Classroom"** learning

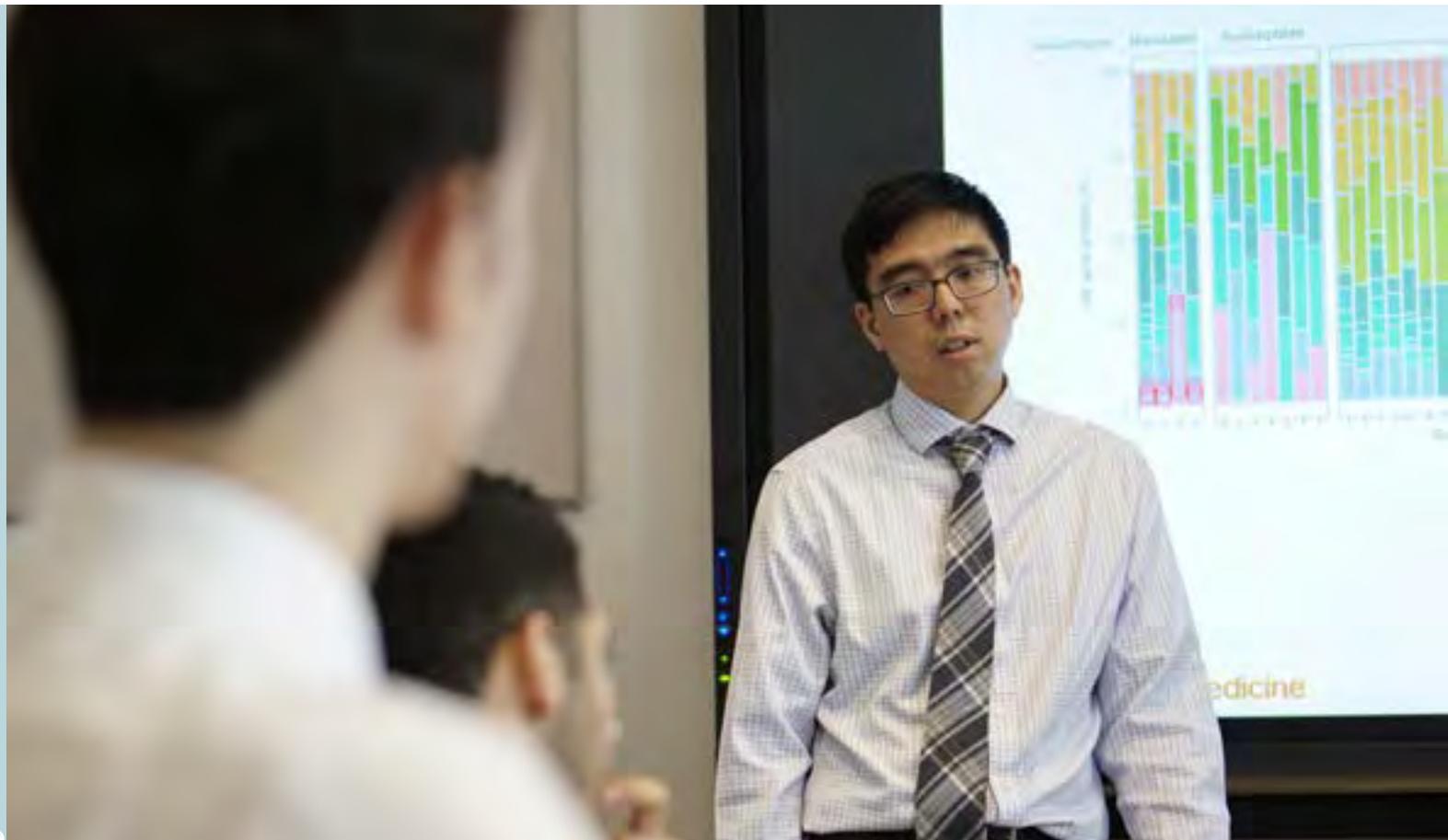
**curriculum**, which included a CME/CE live symposium, preceded by an online activity to help reinforce learning and application for participants.

In FY18, **188 professional education activities** were accredited in various formats, including live conferences, workshops, journal clubs, online webinars, and webcasts, giving NKF the ability to educate **62,851 clinicians**.

# 188

professional  
education activities

educated  
**+62** THOUSAND  
clinicians



## NKF 2017 Spring Clinical Meetings

Nephrology healthcare professionals from across the country come to the NKF Spring Clinical Meetings (NKF-SCM) to learn about the newest developments related to all aspects of nephrology practice, network with colleagues, and present their research findings. It is the only conference of its kind that focuses on translating science into practice for the interprofessional healthcare team, including nephrologists, nurses, technicians, dietitians, social workers, pharmacists, and transplant professionals. In 2017, 2,900 attendees came to Orlando, FL, to learn the latest in kidney care. **New features of the conference included:** partnership with the National Association of Nephrology Technicians/Technologists, who developed a two-day program, including sessions for both patient care technicians and biomedical technologists; new pre-conference courses on kidney stones, palliative care, and vascular access, and a hands-on ultrasound course; ABIM Maintenance of Certification Points offered for selected physician sessions; an increased number of interprofessional sessions; and hosting a groundbreaking PCORI-supported conference. (See page 10.)



## AJKD Welcomes Prestigious Leader

In 2017, **Dr. Harold Feldman** from the University of Pennsylvania in Philadelphia became the new Editor-in-Chief of NKF's *American Journal of Kidney Diseases* (AJKD). Founded as NKF's official journal in 1981, AJKD is recognized worldwide as a leading source of information on clinical nephrology practice and clinical research. Dr. Feldman has made it his mission to make AJKD more international by bringing in editors from outside North America, and to expand the *Journal's* content to include patient-centered outcomes research, health policy, pediatric nephrology, and transplantation.

## Professional Membership

NKF's Professional Councils and Scientific Advisory Board (SAB) create the multidisciplinary educational program tracks at NKF-SCM and are a part of NKF's unique identity and history as an organization serving the entire kidney healthcare team. The Councils and SAB are professional communities, with local chapters, meetings, and events throughout the country. Any healthcare professional who treats patients affected by kidney disease, or who is interested in learning more about nephrology, is invited to join.

In addition to supporting healthcare professionals, being a member also helps support the many programs and resources we offer patients, and supports our research grant endowment fund, so we can continue to support young scientists in the fight against kidney disease.

NKF Members connect not only as colleagues, but also to the profession itself and its developments nationwide. **NKF Member Benefits** enhance this connection: subscriptions to NKF journals and publications (such as the *American Journal of Kidney Diseases*, *Advances in Chronic Kidney Disease*, the *Journal of Renal Nutrition*, the *Journal of Nephrology Social Work*, *RenaLink*, and *Membership Today*); professional e-tools and clinician support materials through our Professional Education Resource Center (PERC); access to free CME/CE activities; savings on all educational programs, resources, and items in the NKF online store; a chance to receive special NKF awards, scientific research grants, and educational stipends, including the prestigious Fellowship of the National Kidney Foundation (FNKF); and eligibility for professional designations and certifications.

[kidney.org/professionals/membership](https://www.kidney.org/professionals/membership)

# WHEN THE DOCTOR NEEDS A KIDNEY

## *The Story Behind 4 Billboards in Cleveland, Ohio*

72 is not a lucky number if your kidneys fail. That was Dr. Peter Greenwalt's age when his long-term type II diabetes caused kidney failure. He was not alone with this problem. Elderly people with kidney failure are on the rise<sup>1,2</sup> and in fact, are the population with the highest incidence of ESRD.<sup>3</sup>

Dr. Greenwalt, a Cleveland MD who specializes in gastroenterology, seemingly had an advantage. He knew how to do the research and explored all options for getting a transplant, finding several programs with shorter wait lists, and sent out the recommended S.O.S. to relatives, friends, even strangers. "I learned how hard it was to ask people for small favors, much less asking for a HUGE favor," says Dr. Greenwalt. He even had the extra advantage of having another doctor as his wife.

Peter was blessed with many good friends, but not a matching kidney. Friends, office colleagues—even his own patients—stepped up and volunteered, including his wife of 47 years, Dr. Bobbie Baetz-Greenwalt.

Dr. Greenwalt signed up for the national wait list. The wait for a deceased donor kidney in Cleveland is six years. Because of his age, Dr. Greenwalt also signed up for extended-criteria donor pools. Extended-criteria donor organs have some risk factors, such as older age, high blood pressure, obesity, organs that have been through a delay before they were transplanted, suboptimal organ function, and nontraumatic causes of donor death.

While waiting for a possible transplant, he began preparing for a life on peritoneal dialysis, and was set to have the surgery to have a catheter placed.

Then along came a friend.

A donor (who wishes to remain anonymous) had offered a kidney to Dr. Greenwalt when he first found out that type II diabetes was damaging his kidneys. Now, when his kidneys had failed completely, she offered again. Dr. Greenwalt doesn't hold back when describing her: "She is an ange!!!!!"

Post-transplant, Dr. Greenwalt's good luck has held, and he describes himself as "doing spectacularly.... I have regained all my lost energy, and with working out, feel 15 years younger." He can't find enough words to thank his donor and her family—and his own family, friends, and patients—and NKF—for their support. He participates in every Northeast Ohio Kidney Walk, and is a Top Fundraiser for his local office. He also puts his professional skills to work for NKF, volunteering at NKF KEEP Healthy kidney health checks and hosting NKF Serving Northern Ohio's first Hero Circle event in FY18. He also contributed \$10,000 towards Hero Circle making him NKF-NOH's first Champion-Level sponsor.

Dr. Greenwalt's goal is to change someone's life by finding them a kidney, and he has initiated that effort by purchasing four billboards in the Greater Cleveland market, dedicated to living donation and the Kidney Walk, for public awareness.

The billboards were Dr. Greenwalt's idea. During a conversation with Anna Tzinis, NKF-NOH's Executive Director, about wanting to raise awareness about living donation, he decided to purchase four billboards targeting medically underserved areas of Cleveland for National Kidney Month in March 2018. The goal was to raise awareness about living donation, NKF, and kidney health. The billboards were a big success, and he recently said that he wants to make this an annual tradition. "I would like to see at least one person find a donor and be as fortunate as I have been."

As a transplant recipient himself, he now aims to be the "poster child of transplant" and help others find their own voice for living donation.

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### Sources:

1. <http://cjasn.asnjournals.org/content/5/11/1910.full>
2. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2849001/>
3. <https://www.kidneynews.org/kidney-news/special-sections/geriatric-nephrology/kidney-transplantation-in-the-elderly>



Your second kidney,  
her second chance.

LEARN ABOUT LIVING KIDNEY DONATION  
kidney.org • 855.NKF.CARES

"I would like to see at least one person find a donor and be as fortunate as I have been." ▶ **Dr. Peter Greenwalt**

# “BUYING-IN” TO KIDNEY HEALTH

## **Funding means change—**

NKF is making an effective case for the importance of kidney health—and for the millions of Americans with CKD and at risk. Individuals, businesses, government, and other organizations are now understanding the urgency of this issue, and stepping forward with financial support, making more of our work possible. Without philanthropic support, expanding research, removing barriers to lifesaving transplants, updating kidney healthcare education, improving lives of dialysis patients, and driving earlier detection could not happen. But more work always needs to be done. Every breakthrough leads to another opportunity to help more people. Our funders partner with and trust NKF to deliver on our mission, to expand our reach, and to improve the lives of those we serve.

## **HOW** People Support NKF

The vast majority of NKF’s financial support—over 70 percent—comes from people like you who understand the importance of kidney health, the urgent need for more kidneys for transplantation, and the financial and personal costs of kidney disease to society. (See pages 59, 66 on individual donors.) We raise funding through our annual campaign, events such as NKF Kidney Walks and NKF Konica Minolta Golf tournaments, employee matching gift programs, social media and email campaigns, corporate sponsorships and partnerships, and planned giving, along with other sources of support.

### **Hero Circle—People Making Our Mission Happen**

Hero Circle is NKF’s new giving society made up of committed individual donors who invest in our mission by supporting our annual fund with leadership contributions of \$1,000, \$5,000 or \$10,000. It is with their unwavering support that we are able to have an impact on the lives of patients, their friends and families throughout the country.

For a list of our current Hero Circle Members, see page 66.

### **Workplace Giving**

Many city, state, federal, and private companies provide [workplace giving campaigns](#) to support their employees’ philanthropy. Employees can support

charities like NKF and give a one-time contribution, set-up monthly payroll deductions, and request a corporate matching gift, if offered.

### **Employees Helping Patients**

[NKF’s NEW Drive for Dialysis program](#) already has momentum, providing nearly 4,000 care packages to patients across the country and raising thousands in partnership with dedicated corporate sponsors and their employee volunteers. The program, which allows organizations to educate their workforce about kidney health while providing the tools to assemble care packages for dialysis patients in the community where they do business, has been adopted by major national organizations and includes

Konica Minolta, Medtronic, OptumRx, and LogistiCare. The program continues to expand and draw new partnering organizations.

### **Leaving a Legacy of Hope**

Understanding the true scope and impact of kidney disease creates a strong motivation among many people to leave a lasting legacy to support NKF’s mission and vision. Individuals making planned gifts to NKF are recognized in our [Legacy Society](#) and create a ripple effect, touching the lives of those affected by kidney disease, now and well into the future. NKF’s versatile [Planned Giving Program](#) offers many opportunities to invest, including wills and trusts, retirement plans, life insurance, and estate plans.

## Events!

With more than 300 NKF Events happening in FY18, the kidney community came together to walk, golf, party, and fundraise their way!

### **Kidney Walks on the Move, Picking Up the Pace!**

Tens of thousands of walkers come together every year and create a Kidney Walk community of hope and support. Kidney Walks are leaving bigger footprints than ever across the U.S., through fundraising and local awareness. The nation's largest fundraiser to fight kidney disease included nearly 100 locations across the country and had the best season yet in FY18, welcoming its largest national sponsor to date.

Our Kidney Walk National Partner Program exceeded more than \$1.2 million for the first time in FY18. We welcomed three new national teams, one of which, Fresenius Medical Care North America (FMCNA), raised more than \$284K.

FMCNA, the nation's leading renal care company, is National Presenting Sponsor of the 2018 Kidney Walk series. The partnership has set an ambitious goal for FMCNA to contribute \$750,000 this year toward kidney disease research and support. Last year, more than 3,700 FMCNA employees joined 260+ teams at 74 Kidney Walks across the country, raising more than \$284,000—the

most ever by a National Team—and surpassing the \$250,000 company goal. Since 2012, nearly 14,000 walkers from Fresenius Medical Care-affiliated teams have raised more than \$1 million in the fight against kidney disease.

The top five Kidney Walks for FY18 were Silicon Valley, Philadelphia, Boston, Detroit, and New York City, raising nearly \$3 million combined, and collectively had more than 10,000 participants!

### **NKF Konica Minolta Golf Classic**

NKF's golf program secured a new title sponsor, and a new name: the NKF Konica Minolta Golf Classic. Konica Minolta's CEO Rick Taylor, a kidney cancer survivor, joined us at our National Finals at Pebble Beach. Our golf tournaments are popular with corporations as a way to entertain current clients and network with potential leads. Because of our strong partnership with Konica Minolta, the golf program is growing and reaching more corporate influencers who support our cause. Together, we're taking a swing at fighting kidney disease!

Also in FY18, we introduced a new fundraising initiative for golf, led by pro-golfer Bryson DeChambeau. Bryson's Birdie Challenge asked donors to make a fundraising pledge for each birdie Bryson made during his April tournaments. (See page 33.)



▲ Clark Taylor, John Starks, Rick Taylor, Steve Rhorer, and John Fahey at the National Finals at Pebble Beach. (See page 48.)

### NKF Fundraising on Social Events

The NKF Social Events happen in a variety of formats, from traditional galas to creative chef events to honors events. New possibilities show up all the time and they continue to grow in popularity and revenue! In this last fiscal year, we launched a brand-new website, and worked to strengthen the social events brand. (See page 33.)

### Team Kidney: Your ideas. Your passion. Your way.

Team Kidney, which lets people fundraise their way, celebrated its first birthday in FY18 and welcomed 300+ campaigns, including ten Partnership Events, such as the New York City Marathon, the Twin Cities Marathon, and NYC's Five Boro Bike Tour. Facebook launched its own DIY fundraising platform, and NKF took full advantage, raising more than \$500,000 in its first year. Also, see how NKF local offices are raising support and awareness on page 50.

**Kidney Cars:** *The oldest, the most trusted—and best—car donation program!* In FY18, more than 7,600 vehicles were generously donated through the Kidney Cars vehicle donation program. The highest-grossing vehicle was a 1968 Rolls Royce Shadow for \$15,250.



▲ NKF Chair Art Pasquarella with his daughter Jessica and son-in-law Kevin Hinds at NYC's Five Boro Bike Tour.



▲ The Second Annual San Francisco Kidney Ball was hosted by the Young Professional Board in March 2018. The Board, made up of young professionals from the Bay Area, has been an integral part of the San Francisco Kidney Ball's soaring success.



▲ Guests dressed the part for the speak-easy-themed 2017 Magic of Giving Gala in Kansas City.

### NKF Corporate Partners

Partnerships between nonprofit and for-profit organizations are strategic alliances that allow both organizations to expand company and brand interest to new audiences. NKF has a long history of successfully partnering with both industry and consumer companies to raise awareness about kidney diseases and transplantation, while offering educational and promotional resources to meet corporate objectives.

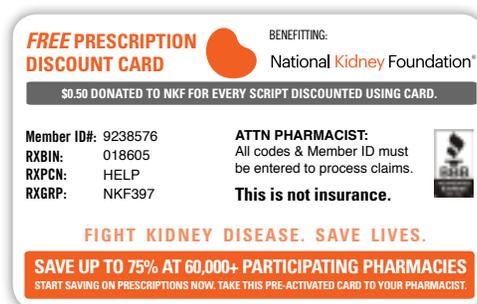
Corporate Partnerships, whether small or large in scope, offer a variety of ways for companies and their employees to get involved through:

- Co-branding and Strategic Alliances
- Corporate Membership
- Cause Marketing Campaigns
- Event and Program Sponsorships
- Workplace Giving and Employee Engagement Programs
- Media Partnerships

### Prescription for Supporting NKF

*A unique, new national partnership*

NKF and [Watertree Health](#), the leading provider of free, prescription discount cards benefiting nonprofits year-round, have formed a groundbreaking national alliance. A new prescription discount card program benefiting NKF not only builds awareness of CKD, but will make prescriptions more affordable for anyone, including those at risk for or impacted by CKD. Each time someone saves money using the card, Watertree Health makes up to a 50-cent donation to NKF—at no cost to the cardholder. The card can save up to 75 percent on most brand-name and generic medications at 60,000+ pharmacies nationwide. A comprehensive, year-round marketing campaign features targeted messaging directed to various constituents, including at-risk individuals, patients, healthcare professionals, and corporations.



## WHY These People are on NKF's Team

*Because they know the huge impact that kidney disease is having on all of us—now:*

- ▶ Because one in seven adults have CKD. That's 30 million people, 15 percent of the adult population.
- ▶ Because 90 percent of people with active kidney disease *don't* know they have it—until their kidneys fail.
- ▶ Because every day time runs out for 13 people on the transplant wait list.
- ▶ Because the financial costs of kidney disease to taxpayers are mounting—over \$100 billion a year and increasing.
- ▶ Because many of our funders and supporters know firsthand what it is to live with kidney disease, whether it's themselves, a family member, or someone they love.
- ▶ Because people are counting on us to make progress.
- ▶ And because NKF keeps their hope alive through our work.

At NKF, the time is always *now* to take the next action—

# WHAT We Could Do With More Support—

People trust NKF because we take action, convening the right partners to accelerate needed change.

We first defined kidney disease as a treatable illness. We revolutionized kidney disease treatment, setting standards through the KDOQI Guidelines. We are now making major breakthroughs with THE BIG ASK: THE BIG GIVE, and CKDintercept, and by leading collective action with stakeholders. NKF has the structure in place and, with the right support, we are poised to transform the world of kidney health.

## ► Save More Lives

By making more kidney transplants available. By finding kidney disease earlier. To start, further funding could help more people waiting for a kidney find their living donor through expanding THE BIG ASK: THE BIG GIVE (BAG) trainings throughout the country. This proven, effective initiative is already saving lives and could save more with greater financial support. We could further expand this platform by creating targeted, online “virtual trainings,” expanding to non-English speaking populations, and by increasing follow-up support to improve results.

100,000 Americans are on the wait list right now; 3,000 deceased donor kidneys are discarded each year. We’ve

only just begun our efforts to free up this untapped resource. Funding for research and nationwide initiatives could help increase utilization of these kidneys, and translate into people being immediately taken off the list and truly getting on with their lives.

NKF’s largest initiative to date, CKDintercept is already changing the world of kidney healthcare and on its way to finding millions of patients with undetected CKD, detecting and treating earliest-stage kidney disease in primary care, and creating a culture of protective care. This program needs funding to reach its fullest potential.

Taking “The Fight” to the state level—funding state-level advocacy changes laws to make it easier—or even possible—for someone to donate a needed kidney. While we continue to advocate for the Living Donor Protection Act in Washington, DC, we are having successes at state levels with similar legislation. Idaho recently passed living donor legislation and, with support, others could follow, saving lives in entire state populations. Amplified state-level advocacy for paid leave policies may further increase the number living donations. State kidney advocates could also better defend and expand state budgets for research and healthcare.

## ► Improve Lives, in Real-Time

Living with kidney disease is a stressful, daily challenge for both patients and their families. Supporting these people and improving their quality of life is one of the most important parts of our work. With additional funding, NKF Cares Help Line could improve and expand its services for distressed patients and their families dealing with the difficult realities of this disease, by extending our capabilities and tools for faster response time and follow-up, and upgrading to the latest call center/customer support technology, including live chat on our website.

We could improve the technology to match more kidney transplant recipients and potential donors with Peers program mentors. We could also expand this important source of support to caregivers, family members, parents, teens, and kidney cancer patients.

Expanded NKF online communities: NKF online communities offer a safe and supportive place where patients and caregivers can share experiences, ask questions, and get answers related to kidney health, kidney disease, transplantation, and living organ donation. Currently, groups cover kidney disease, dialysis, transplant, and donors. In FY19, we rolled out a new pediatrics forum, Parents of Children

with Kidney Disease. This cost-effective and targeted resource could be expanded further.

## ► Reach More People

Starting with children. Almost 10,000 children and adolescents in U.S. are living with end-stage renal disease. They are 30 times more likely to die than healthy children. NKF needs support in helping these patients live out their lives, through research, such as the upcoming NKF Controversies Conference on CKD and Children; early health interventions; improved treatment; targeted BAGG living donation campaigns; and assistance to parents managing their children’s illness, such as our new online community, Parents of Children with Kidney Disease. Funding NKF pediatric initiatives is a priority because people beginning their lives with kidney disease should get a better chance at a better life.

We could help more where it’s needed most. CKD hits African Americans, Latinos, Asians, Pacific Islanders, and Native American populations at higher rates. Many of these populations are underserved by the healthcare system. It is imperative that we continue to extend our outreach to these populations as much as possible to truly fulfill our mission. Funding expanded KEEP Healthy kidney health checks in diverse communities, multilingual

Your Kidneys and You educational programs, research into disparities in minority transplant rates, and expanded bilingual public awareness efforts, such as our recent Spanish-language living donation PSAs, are just a few of the ways we could improve the lives of the people affected most by kidney disease.

### ► Improve Treatment and Move Closer to a Cure

Research drives change; funding drives research. We could make major investments in pure research, a key part of our basic purpose as a foundation. Virtually all of our activities are backed by research, from what we say to patients on the NKF Cares Help Line, to the content of THE BIG ASK: THE BIG GIVE in-person trainings, to government advocacy. Funding for research supports our entire mission activities and drives improved treatment and eventually a cure.

*One of these investments would involve setting up a CKD Clinical Trial Consortium, similar to what we successfully did in 2010, with the CKD Prognosis Consortium, for observational cohorts. The new Consortium would be led by the world's foremost clinical epidemiologists, and would gather the patient-level data from all of the recent clinical trials that included kidney disease end points. With this data and with the creative energy of these investigators, we would be able to develop new, evidence-based tools that*

*would help sponsors design better, less expensive clinical trials, and thus enable many more trials of promising therapies to be conducted, faster and with a much greater likelihood of successful outcomes. It is time that we had specific medicines for kidney disease!*

We could further "invest in the future" by increasing the number of Young Investigator Grants, which encourage the best scientists to enter the field of kidney research. An investment in a beginning scientist's project can be the start of many significant contributions to kidney research over their entire careers. This is crucial to our efforts to fight kidney disease.

Dialysis patients could live better lives. Most end-stage renal disease patients have to travel to a dialysis center three to four times a week. This truly defines "burden of illness," involving travel, wait-times, and disruption of work and lives around scheduled times. Home dialysis is a life changer for kidney patients. NKF's recent Home Dialysis Conference and upcoming follow-up conference only represent the beginnings of what we could do in this area that has a direct impact on the lives of kidney patients.

Finally, with major funding we could enact a strategy to transform and expand NKF's research program to facilitate and expedite a cure for kidney disease.

*NKF has the experience, the knowledge, and the passion; our impact on the lives of patients and the public is only limited by the amount of financial resources we receive. If a few "what ifs" become realities, a world of kidney disease can become a world of kidney health.*



# ON THEIR GAME FOR KIDNEY HEALTH

## **Two NBA Legends Play on Defense Against Kidney Disease—At a National Golf Tournament!**

Basketball met golf for a win against kidney disease. “Millions of people with kidney disease” isn’t just a statistic to NBA-er Allan Houston. The legendary Knicks shooting guard and Olympic gold medal winner has a personal stake in the game that prompted him to support and participate in the National Kidney Foundation Konica Minolta Golf Classic National Finals in January 2018. Because his father, fellow NBA legend and coach Wade Houston, was hit by kidney cancer several years ago, Allan wanted to help prevent others from suffering like his Dad. He decided to hit the links to benefit NKF programs and to move us toward a real win—a cure for kidney disease.

Houston, now NY Knicks Assistant General Manager and Westchester Knicks General Manager, joined hundreds of golfers from across the country in the 31st annual competition to promote kidney health, fight kidney disease, and support living organ donation. Declaring, “Together we can make a difference,” Houston, former #20 during his NBA career, raised funds through the NKF Birdie Challenge by encouraging his friends and

fans—Team H2O—to pledge \$20, or any dollar amount they could, for each birdie he made. In addition to golfing with event participants, The Allan Houston Legacy Foundation (AHLF) auctioned a special New York Knicks Tickets Together Game Experience to raise additional funds for NKF.

Allan wasn’t the only sports star at Pebble Beach, CA, that day. He was playing “combination defense” against kidney disease with his buddy, former Knicks All-Star and NBA player John Starks who supports Allan in his charitable work—teammates on the court and now on the links! Coach Wade Houston was there, too, as unofficial overseer of the pair. And they were all backed by their crew across the nation, Team H2O.

John Starks also played several rounds of golf, and to raise even more, the John Starks Foundation donated its own auction experience: a golf foursome (three players matched with a celebrity from the sports/entertainment worlds) for the 23rd Annual John Starks Celebrity Classic, held in Connecticut.

NKF CEO Kevin Longino, who received a kidney transplant 13 years ago, joined Houston and Starks in the day’s golf action. “We welcome Allan and John to this year’s National Finals. I am excited to team up with them to emphasize the importance of living organ donation,” Longino said. “I look forward to the opportunity to play in support of greatly improving the lives of kidney patients and preventing kidney disease.”

Allan’s inspiration and motivation, his father Coach Wade Houston, is a legend in his own right. Coach Wade, the first African-American basketball coach in the Southeastern Conference and a kidney cancer survivor, is a true testament of faith and resilience.

Allan also has a further personal understanding of how living organ donation saves lives. “One of my best friends donated one of his kidneys to his wife and drastically improved her life. That’s why I am proud to partner with the National Kidney Foundation,” said Houston, who also is raising money for AHLF, which aims to transform the lives of young people by training

youth-facing leaders around the values of FISLL (faith, integrity, sacrifice, leadership, and legacy). Allan’s friend, Maxwell Tinsley, also showed up at Pebble Beach and was an especially inspiring Mission Speaker on Gala Night as well.

John Starks recently had his own close encounter with the issue of transplantation when he visited with Matthew Francis of Queens, NY, a teenage kidney transplant recipient and upcoming basketball player who was sidelined by his disease and recently cleared to return to the sport he loves. After marveling at the now-healthy 14-year-old’s 6’ 3” height, Starks offered encouragement and advised the young athlete on how to keep an eye on the other players.

For Allan and John, their post-game careers include being all-stars to people with kidney disease.

[To find out more about NKF Konica Minolta Golf Classics, go to page 43.](#)



“One of my best friends donated one of his kidneys to his wife and drastically improved her life. That’s why I am proud to partner with the National Kidney Foundation.” ▶ **Allan Houston**

Allan Houston  
and John Starks ▶



# NKF ALL OVER THE MAP:



## NKF SERVING THE NORTHEAST

### NKF Serving Greater New York

NKFGNY educated over 400 medical professionals through Grand Rounds, Council Meetings, and an Annual Regional Symposium. Local Team Kidney members raised upwards of \$200,000 through various campaigns, including a record-setting effort at Law Rocks.

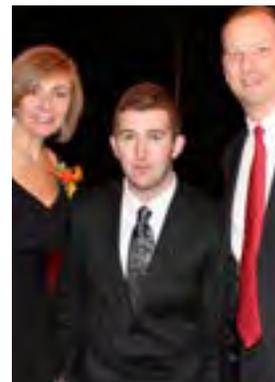
The Meltones, of Greenberg Traurig, LLP, performing at Law Rocks in NYC, November 2017. The Meltones won the night for the fourth straight year, raising over \$42,000 for NKF. ▼



### NKF Serving Upstate and Western NY

NKF UP & WNY had a meaningful community impact by distributing over 3,000 kidney-related materials, educating 110 patients and caregivers on renal nutrition, providing continuing education credits to 200 social workers and renal dietitians, and doing health checks on 150 people in high-risk communities.

AnnMarie Link with her son Kyle, who is the recipient of a kidney donation from his father, Larry (right), at the Honors Awards Benefit. AnnMarie and Larry were honored as Outstanding Volunteers of the Year. ▼



### NKF Serving New England

NKFNE held an Innovation Meeting at MIT's Sloan School of Management, Cambridge, MA, in December 2017. A small group of tech "game changers" gathered to apply their ideas to bring new, non-traditional methods to "hack" kidney disease. The event resulted in new program ideas, identification of new board members, and potential partnerships.

NKF Serving New England Honors reception, for outstanding members of the local medical community and a Kidney Hero, at the Harvard Club, Boston. ▼



### NKF Serving Connecticut and Western Massachusetts

NKF CT & W/MA hosted their first Drive for Dialysis program at Achillion Pharmaceuticals in December during Achillion's annual meeting. Seventy-five employees were educated about kidney disease while filling 100 care packages to be sent to local dialysis unit patients to brighten their spirits.

Sandra Boccuzzi receives some love from Drive for Dialysis. ▼



## Moving the Mission Forward

Check out these highlights of what the NKF Team has been doing across the nation in FY18!

**NKF Serving the Delaware Valley (Philadelphia)**

NKF DV hosted their 10th Annual Mid-Atlantic First-Year Renal Fellow Symposium and, thanks to the support of their corporate partners, distributed 250 dialysis care kits throughout the region.

Pentec Health employees assemble dialysis care kits. ▼



**NKF Serving the Alleghenies (Pittsburgh)**

NKFALG advocates in Pennsylvania sent more than 1,750 letters, emails, tweets, and calls to legislators in support of kidney disease funding. This outreach led state legislators and the governor to only reduce the Chronic Renal Disease Program by \$1 million, instead of the proposed \$6.6 million cut. They also held a new NKF Corporate Monopoly® Tournament with 150 players, raising nearly \$40,000; the Gift of Life Gala Mission Moment raised a record-breaking \$50,000+ in 10 minutes!

NKFALG Kidney Gala. ▼



**NKF Serving Maryland and Delaware**

NKFMDDE served nearly 6,400 participants through their health screenings and outreach events. Corporate sponsorships made it possible for 300 care packages to be distributed to patients through the Drive for Dialysis program.

Drive for Dialysis event, Lutherville, MD. ▼



**NKF SERVING THE MID-ATLANTIC**

**NKF Serving Virginia**

NKFVA, Richmond, had a strong year. Over 300 people were screened at one KEEP Healthy event early in the year. Thanks to one of NKFVA's sponsors, in June their golfers had the privilege of having a PGA pro join them on the golf course at their tournament. Another highlight was the opportunity to honor four dedicated members of their kidney community. At a wonderful event on World Kidney Day, NKFVA recognized a generous donor in the business community, a tireless advocate, a selfless volunteer, and a long-time and well-loved nephrologist.

L-R: Kathy Headlee, Chuck Baker, Robyn Jones, Dr. Todd Gehr. ▼



**NKF Serving the National Capital Area**

NKF NCA's year was characterized by building and strengthening partnerships—including local sports teams, transplant centers, and community groups—to raise awareness about kidney disease and organ donation and to do health checks on those at risk.

Seven-year-old transplant recipient Stephen Schwartz throws out the first pitch at a Washington Nationals game. ▼



**NKF Serving Kentucky**

NKF KY had perfect weather and nearly 50 teams for the 2017 NKF Konica Minolta Golf Classic at Hurstbourne Country Club, raising over \$150,000.

NKF KY hosted two CKDinform: Early Detection and Prevention three-hour symposiums this year. They welcomed 84 medical professionals, each leaving with the knowledge and resources to improve their ability to detect CKD.

Konica Minolta staff. ▼



**NKF Serving  
Greater Cincinnati**

NKFGC hosted their first THE BIG ASK: THE BIG GIVE in-person training at the University of Cincinnati Medical Center on World Kidney Day, the first of four in-person trainings annually that partner with all three of the city's transplant center hospitals, as well as their local organ procurement organization.

Welcome to NKF's THE BIG ASK: THE BIG GIVE in-person training, sponsored by UC Health. ▼



**NKF Serving  
Northern Ohio**

NKFNOH had a year of firsts—holding its first THE BIG ASK: THE BIG GIVE in-person training; its first Hero Circle event; and its first Pediatric Awareness event. NKF Serving NOH increased their KEEP Healthy health checks numbers by 414 percent from the last fiscal year.

THE BIG ASK: THE BIG GIVE transplant/donor in-person training. ▼



**NKF Serving  
Central Ohio**

NKFCO successfully held their annual Kidney and Transplant Symposium, hosting over 300 renal professionals from Ohio, Kentucky, Indiana, Pennsylvania, and West Virginia. They concluded FY18 with the Central Ohio Patient Summit—which was open to all patients, caregivers, and renal professionals—and a very active National Kidney Month.

National Kidney Month kickoff with Nationwide Children's Hospital's transplant and nephrology staff. ▼



**NKF Serving Minnesota**

The NKFMN office saw record attendance at Donor Day with the Minnesota Twins, and 100 people attended their first-ever Orange Party for kids with CKD.

NKF supporters enjoying Donor Day at a Minnesota Twins event. ▼



**NKF OF  
INDIANA**

NKF of Indiana hosts a Kidney Camp for children every year. They have partnered with Manchester University School of Pharmacy. A course that allows the pharmacy students "hands-on" education about kidney disease and provides medication distribution to the campers has been a terrific success!

Manchester University Pharmacy School students earn college credits for providing pharmacy oversight for campers at the NKF of Indiana Kidney Camp. ▼



**NKF OF  
ILLINOIS**

Sheila Williams has given life to her daughter Teliyah, twice. First in January 2006, when Teliyah was born, and again in December 2017, when Sheila gave her 11-year-old daughter a kidney. NKF of Illinois walked Sheila and Teliyah through the complicated process of dialysis and living kidney donation.

In 2018, NKFI launched two new programs for youth: Kids with Kidney Disease & Transplantation, and Teens & Young Adults with Kidney Disease & Transplantation. These programs are free for kids and family members.

Sheila and Teliyah. ▼



## NKF OF MICHIGAN

NKFM had a successful year, directly serving more than 80,000 people through prevention programs and services. The lives of thousands more were touched through fundraising events, educational messages, and community outreach.

Wearing orange for World Kidney Day. ▼



## NKF OF WISCONSIN

NKFW, celebrating its 50th Anniversary, is proud to have collaborated with The Wellness Network to create the *Nephrology HealthClips*, a kidney educational video series available nationwide in over 3,000 healthcare facilities.

Saving lives since 1968. ▼



## NKF SERVING CENTRAL U.S.

### NKF Serving Oklahoma

The second annual Oklahoma City Kidney Walk was held at Stars and Stripes Park. Over 400 attendees were on hand to support the mission of NKF and to bring awareness of CKD. The event had as its inaugural Corporate Walk Chair, Steve Merchant, Vice President of SORB Technology, a subsidiary of Fresenius Medical Care.

LogistiCare employees kick off the annual Oklahoma City Kidney Walk. ▼



## NKF Serving Kansas and Western Missouri

### Kansas City

The Kansas City office held their inaugural Renal Roundtable lecture series, inviting distinguished presenters to speak with 100 local physicians and advanced practitioners for three dinner sessions.

The first annual Kidney Social Summit patient education program hosted 50 patients, caregivers and family members who learned about various kidney-related topics. Attendees were also able to make kidney-friendly recipes alongside renal dietitians.

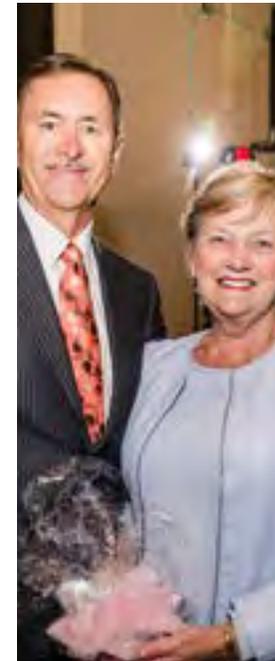
Dr. Aditi Gupta speaks with Dr. John Scandling in advance of his lecture. ▼



## Wichita, KS

Wichita had another record-breaking Great Chefs of the Midwest event. Nearly 200 people gathered at Distillery 244 to enjoy cuisine from local chefs and restaurants. The evening was chaired by Dr. Dennis and Ann Ross, Dr. Joe and Linda Davison, and Chef Josh Rathbun, kidney transplant recipient.

Dr. Dennis and Ann Ross enjoying the Great Chefs of the Midwest event. ▼



## Hays, KS

In partnership with volunteers from Celebration Community Church, the local NKF chapter hosted a kidney health check and health fair in Hays. It was the community's first-ever kidney health check event.

A volunteer takes the blood pressure of a participant. ▼



**NKF Serving Eastern Missouri (St. Louis)**

Over the past year, NKFEMO collected patient photos and stories, through events, social media, direct outreach, and a volunteer professional photographer, to demonstrate NKF's impact and put a face on CKD. The photos and stories premiered at the Gift of Life Gala as an Honor Wall.

Gift of Life Gala Honor Wall. ▼



**NKF Serving Iowa and Nebraska**

NKFI&N had an exciting year, celebrating Kidney Month, launching a program delivering gifts to pediatric patients, and breaking the fundraising record at their NKF Kidney Walk by almost 10 percent over last year. Their Konica Minolta Golf Classic raised \$199,000 and was the number-three net event in the country.

Team Gee Force at Central Iowa Walk event at Raccoon River Park. Winner of a weekly, "Who's Raised the Most Money This Week?", they lead the Walk. ▼



**NKF Serving Colorado, New Mexico, Montana, and Wyoming**

NKFCO launched their first Renal Roundtable speaker series with 60 medical professionals in attendance and \$20,000 in new sponsorships. NKFCO also had a record-breaking year for their 35th Annual Great Chefs of the West, with over 550 people in attendance and \$30,000 over goal.

Team Maffia firefighters walk in the Colorado Springs Kidney Walk. ▼



**NKF Serving the Dakotas**

NKFD focused on outreach through hosting KEEP Healthy health checks in Sioux Falls and in a new market, Fargo. They are also working on educating patients with 16 Kidney Resource Centers throughout the region.

National Kidney Month kickoff in Sioux Falls. ▼



**NKF SERVING TEXAS AND THE SOUTHEAST**

**NKF Serving East and Middle Tennessee**

NKF-EMTN raised over \$140,000 at their three Kidney Walks and held their most successful KEEP Healthy event to date, doing kidney health checks on 127 participants!

NKF-EMTN on the go with Kidney Walks. ▼



**NKF Serving West Tennessee**

NKFWTN had another great family fun event, the Chocolate Fantasy fundraiser, giving over 30 local chocolatiers the opportunity to showcase their delectable chocolate specialty pastries, candies, and sweet/savory creations, with over 1,000 true "chocololics" in attendance.

NKFWTN Chocolate Fantasy event. ▼





**NKF Serving  
North Carolina**

NKFNC educated over 900 people through KEEP Healthy, Your Kidneys and You, and Patient Empowerment Workshop events. In March, 300 guests attended the third-annual North Carolina Kidney Gala, the most successful edition of the event yet.

Sidney plays host at the 2018 NC Kidney Gala. ▼



**NKF Serving  
South Carolina**

NKFSC was proud to host a Patient Empowerment Workshop in Charleston, SC. More than 130 dialysis patients were empowered with knowledge of physical activity and proper nutrition. And, throughout the year, over 850 people were directly educated about the importance of kidney health, and 355 people were given kidney health checks.

Patients and their caregivers enjoying a day of learning and understanding at the Patient Empowerment Workshop. ▼



**NKF Serving  
Georgia, Alabama,  
and Mississippi**

NKFGAM has given health checks to 584 people through KEEP Healthy, which is a 16 percent increase from the year before. NKFGAM began a partnership with the Georgia State Medical Association, presenting CKDinform to over 70 physicians at their summer conference.

SNPhA volunteer group at a KEEP Healthy. ▼



**NKF Serving Texas  
Austin**

The Austin Kidney Walk, which was featured live on local Fox 7 News, was held at Concordia University Texas in November 2017 with more than 700 participating. Evening anchor, Rebecca Thomas, returned as spokesperson and hostess for the Walk, and shared her story of donating a kidney to her mother.

Austin Kidney Walk volunteers. ▼



**Dallas**

For World Kidney Day, NKF's Dallas office and board members were featured in the Dallas County Health & Human Services newsletter. The Commissioner's Court applauded NKF for its community involvement, health efforts, free health checks on World Kidney Day, and relationship with DCHHS.

A World Kidney Day health check was held in partnership with Dallas County Health & Human Services, with 100 health checks.

NKF Dallas was featured in an iHeart Media Interview promoting World Kidney Day, Kidney Walk, and patient education programs.

Development Coordinator Vanessa Garnica; Program Director Amanda Crowley-Rios; Board Member Dr. Ruben Velez, Dallas Nephrology Associates. ▼



**Houston**

NKFTX was awarded a Blue Cross and Blue Shield of Texas Healthy Kids Healthy Family (HKHF) community grant in the amount of \$235,463 to help combat CKD. The project grant will serve uninsured/underinsured communities throughout Texas.

Postponed following Hurricane Harvey, the Houston Kidney Walk returned to the Houston Arboretum and Nature Center in March 2018 with the crowd pledging support. The Walk also welcomed \$15,000 from Presenting Sponsor First Choice Emergency Room.

L-R: Blue Cross and Blue Shield of Texas Medical Dir. Dr. Bharath Thankavel; Exec. Dir. NKF Serving TX, Lorna Hankins; and Sheena Payne, Blue Cross and Blue Shield of Texas. ▼



## NKF OF FLORIDA

2018 marked the Silver, 25th Anniversary of the NKFF Lakeland Konica Minolta Golf Classic. The tournament included three shotgun starts and grossed nearly \$300,000. NKFF distributed \$167,808 during this fiscal year in direct patient aid for patients needing assistance with food, transportation to treatment, utility bills, or rent. In addition, the NKFF has conducted five KEEP Healthy events targeting underserved and high-risk communities.

NKFF Lakeland Konica Minolta Golf Classic. ▼



## NKF OF LOUISIANA

The NKFL participated in 10 health fairs, distributing kidney health information and salt-free, sugar-free spices for renal diets. The 27th Gala honored seven people who made a significant impact serving the organization and kidney patients.

2017 New Orleans Kidney Walk. ▼



## NKF SERVING THE WEST

### NKF Serving Northern California and the Pacific Northwest

NKFNC-PNW hosted a THE BIG ASK: THE BIG GIVE in-person training, in partnership with Swedish Medical Center, in Seattle, WA, welcoming 75 attendees. The presenters included Swedish team MDs, RNs, and social workers, as well as six living donor-recipient pairs. The 29th Annual San Francisco Authors Luncheon, attended by over 750 guests, raised \$140,000 in day-of revenue and \$477,000 total. The Bay Area Kidney Walks welcomed over 2,500 walkers and raised \$650,000.

Sheryl, transplant recipient and BABG presenter, with John, her living, unrelated donor (and neighbor!). ▼



### NKF Serving Southern California and Nevada

NKFSoCal's Drive for Dialysis program offered a meaningful opportunity for corporate employees to prepare care packages for dialysis patients, and through their THE BIG ASK: THE BIG GIVE in-person trainings, helped 65 patients prepare a living donor action plan.

Thermo Fisher Scientific employees work on dialysis patient care packages. ▼



## NKF OF UTAH/IDAHO

NKFUI worked closely with Idaho volunteers and state legislators to pass the landmark bill, The Living Organ Donor Protection Act (S.1302), the first legislation of its kind in the nation, to protect living donors from insurance discrimination. (See page 22.) In addition, NKFUI medical grant recipient, B. K. Kishore, MD, PhD, MBA, FASN, FRSB, was issued a patent for methods of treating diabetes insipidus associated with P2Y receptors.

Idaho Governor Clement Leroy "Butch" Otter signing legislation. ▼





# GET YOUR ORANGE ON!

Orange swept the country on March 8, reminding people everywhere about the importance of kidney health. In observance of World Kidney Day, iconic buildings and landmarks nationwide turn orange, NKF's signature color for kidney disease. ▶



# 2018 NKF CORPORATE INNOVATOR AWARD

## **Keryx Biopharmaceuticals**

*Keryx Biopharmaceuticals is recognized for developing an iron deficiency anemia treatment FDA approved for early-stage chronic kidney disease patients.*



Keryx Biopharmaceuticals has received the 2018 NKF Corporate Innovator Award. The award was presented to Dr. Leslie Meltzer, Vice President, Head of Medical Affairs at Keryx Biopharmaceuticals in April 2018 during the NKF 2018 Spring Clinical Meetings in Austin, TX.

In November 2017, Keryx Biopharmaceuticals received expanded FDA approval of Ferric citrate (Auryxia) tablets to include the treatment of iron deficiency anemia in adult patients with chronic kidney disease who are not on dialysis, making it the only oral treatment option developed and approved specifically for these patients. Ferric citrate was originally approved in September 2014 for the control of serum phosphorus levels in adult patients with chronic kidney disease on dialysis.

“Iron deficiency anemia can negatively impact a patient’s quality of life and is associated with cardiovascular complications and increased

mortality risk,” said Kevin Longino, NKF CEO, and kidney transplant recipient. “Keryx Biopharmaceuticals’ innovative new treatment for iron deficiency anemia is an important therapy for kidney patients. The Corporate Innovator Award recognizes Keryx Biopharmaceuticals’ significant contribution to improving the lives of people with kidney disease and we congratulate them on this achievement.”

People with CKD often have anemia as a result of insufficient iron (called iron deficiency anemia) and do not produce enough hemoglobin, the component of the red blood cell that carries oxygen throughout the body.

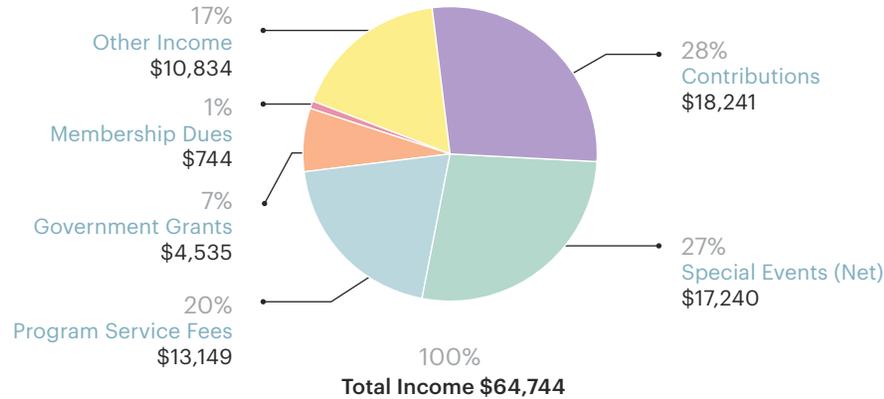
“All of us at Keryx are dedicated to improving the care of people living with kidney disease, and we are extremely proud and honored to be recognized with this award from the National Kidney Foundation,” said Greg Madison, former CEO of Keryx Biopharmaceuticals.

► Dr. Leslie Meltzer, Vice President, Head of Medical Affairs, Keryx Biopharmaceuticals

# FINANCIALS

Figures depict the combined financial activities of the National Kidney Foundation and its Affiliates for Fiscal Year 2018.

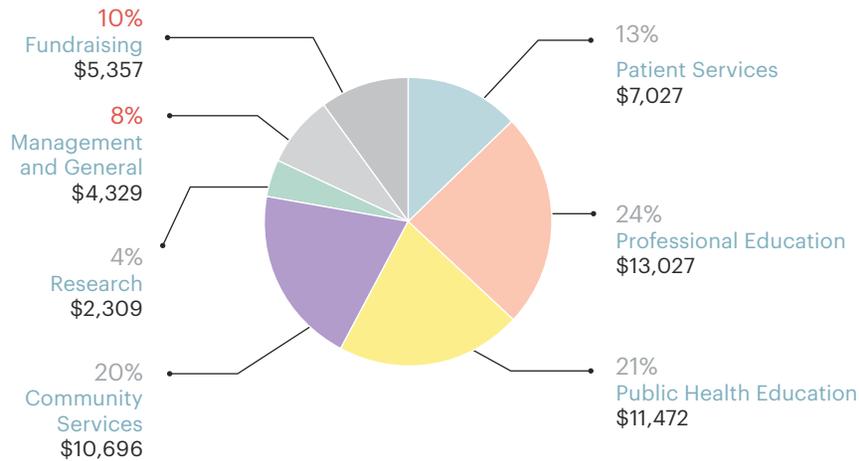
Public Support and Revenue (in thousands)



Assets (in thousands)

Cash and Cash Equivalents	\$9,903
Investments	\$23,806
Accounts Receivable	\$5,061
Inventories of Educational and Campaign Material	\$130
Prepaid Expenses	\$1,683
Property, Plant, and Equipment (net)	\$5,160
Other Assets	\$4,152
<b>Total Assets</b>	<b>\$49,895</b>

Expenses (in thousands)



Total Program Expenses \$44,531 (82%) | Total Support Expenses \$9,685 (18%)

100%  
Total Expenses \$54,216

Liabilities and Net Assets (in thousands)

**Liabilities**

Loans Payable	\$515
Accounts Payable and Accrued Expenses	\$5,493
Deferred Income	\$6,633
Other Liabilities	\$435
<b>Total Liabilities</b>	<b>\$13,076</b>

**Net Assets**

Unrestricted	\$23,805
Temporarily Restricted	\$8,036
Permanently Restricted	\$4,978
<b>Total Net Assets</b>	<b>\$36,819</b>

**Total Liabilities and Net Assets** ..... **\$49,895**

# MILESTONE

## Donald W. Seldin, MD—Distinguished Nephrology Teacher and Researcher

This year, we sadly note the passing of a major figure in the advancement of kidney disease treatment. Donald W. Seldin, MD, founder of the University of Texas (UT) Southwestern Medical School and one of the foremost teachers and researchers in clinical nephrology, passed away in April 2018. Such were his contributions to the field, that each year since 1994, NKF has bestowed the Donald W. Seldin Award, established expressly to recognize and champion excellence in nephrology.

“He was a founding father of nephrology, a visionary leader, and a warm human being who inspired thousands of trainees in his 36 years as Chairman of the Department of Medicine at UT Southwestern Medical School,” says Joseph Vassalotti, MD, Chief Medical Officer of NKF. “He literally transformed

decaying military barracks in 1951 to the world-class medical complex that exists today.”

Dr. Seldin, who was 97, was a major figure in distinguishing nephrology as a discipline and as a clinical and scientific subspecialty, training more than 200 nephrologists during the course of his career. “Many of these nephrologists were inspired by Dr. Seldin to become distinguished investigators and chairs of nephrology departments throughout the U.S. and abroad,” says Dr. Vassalotti.

A New York City native, Dr. Seldin received his BA from New York University in 1940, and his MD from Yale University in 1943. The WWII veteran served in the U.S. Army as a Captain of the Medical Corps from 1946 to 1948. Upon his return to the U.S., after serving in Germany, he

worked as an instructor, then professor at Yale University until 1951. That year, Dr. Seldin joined UT Southwestern Medical School as Associate Professor of Medicine, which launched a long, dedicated, pioneering, and stellar career in clinical nephrology education, research, and leadership. He was a founder of the American Society of Nephrology, one of the seven learned societies around the world to which his peers elected him president. In 2014, at the UT Southwestern South Campus, he enjoyed the singular honor of seeing the dedication of the Dr. Donald Seldin Plaza, complete with a seven-foot bronze statue of himself. More than 400 people, including Nobel Laureates, philanthropists, and campus leaders and physicians, attended the formal ceremony.

“Were it not for the life’s work of Dr. Seldin, nephrology as we know it, and the many advances in the field, would not exist,” says Kevin Longino, CEO of NKF. “What was summed up about Dr. Seldin in our 1990 retrospective book, *National Kidney Foundation: The First 40 Years*, still stands. The passage stated that ‘Nephrology in the United States is what it is today because one day, many years ago, Donald W. Seldin decided to make it his major area of interest,’” Longino quotes.

“Nephrology in the United States is what it is today because one day, many years ago, Donald W. Seldin decided to make it his major area of interest.”

► **National Kidney Foundation: The First 40 Years**

Donald W. Seldin, MD ►



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Transplant Recipient

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## 2018 Board of Directors

The NKF Board of Directors consists of nephrologists, other kidney healthcare team members, civic leaders with diverse business expertise, and people affected by kidney disease. Board members serve a term of three years and may be elected for a second term.

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Professor of Medicine  
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# "OWNING" THE MISSION

## Arthur P. Pasquarella Leadership in Action Award

Courage, faith, and integrity can sound like words repeated in movies and ads—until you meet someone who lives those qualities like our National Chair, Art Pasquarella. Then, the effect is impressive. NKF has had the privilege of being led for the past three years by Art: a great man who lives NKF's mission and embodies the heart behind it.

Under Art's leadership, NKF has led the way in developing innovative approaches to preventative healthcare and patient-centric research, removing barriers to kidney transplantation, and increasing public awareness of kidney disease. He also is NKF's largest individual donor and has brought many other supporters on board.

"Art has always provided professional leadership through his intelligent and thought-provoking dialogue, while always being open to new ideas or concerns to reach a consensus," says NKF Board Member Tom Hough. "His exhaustive personal time commitment to both the National Board and the Philadelphia local board, and his own personal multimillion-dollar financial contributions have earned Art status as one of the most generous, mission-focused individuals in the history of the NKF."

Art is a local and national role model. He has inspired other volunteers to achieve fundraising excellence and increase awareness about NKF's mission. So much so, that we created an award to highlight his contributions and thank him for his service.

**The Arthur P. Pasquarella Leadership in Action Award** is presented by local NKF offices to recognize outstanding accomplishments of volunteers who have demonstrated exemplary dedication through fundraising, program development, or advocacy.

Art's involvement with NKF began with his father and continued with his brother. Valentino H. Pasquarella, Sr., a successful Philadelphia businessman, was struck by kidney disease and started dialysis in the early 1990s. "I watched how he struggled with the physical and emotional rigors of being on dialysis three times per week, four hours each session, while still running his own business. It was a very grueling time for him, who theretofore had been a high-energy, very positive person."

After two years on dialysis, Valentino received a kidney transplant from a deceased donor. "I witnessed firsthand how quickly the transplant transformed him...both physically and psychologically. This left a very powerful impression upon my family and me," says Art.

Valentino received his transplant at 70, extending his life another 12 years, during which he became an NKF supporter.

NKF Serving Philadelphia/Delaware Valley asked Art to volunteer to honor his Dad. A successful businessman like his father, Art put his experience to work for kidney patients and families, serving on the local board. As COO of Equus Capital Partners, Ltd., he inspired many business associates to support NKF. Art maintains his position as a board member for Philadelphia/Delaware Valley. In 2012, Art was elected to NKF's National Board. Art's passion to advance NKF's mission and character so impressed his fellow board members that they elected him National Chair in 2016.

Art experienced a second—and transformative—personal encounter with CKD. Seven years ago, his older brother, Val, Jr., needed a kidney. Art immediately got evaluated and was a donor match. "Without a doubt I knew that if the roles were reversed and if it was I who needed one...he would be the first in line to offer his to me."

Art was glad to be there for his brother, but nervous about the prospect of being a donor. When sharing his story

to help others, Art is straightforward about what he went through and how he felt.

"The evaluation process for being a donor is an emotional roller coaster. I had the following fears: One, they would find something wrong with me; two, I would then not be able to donate to my brother and hence not be able to help him; three, the embarrassment among family and friends of having to back out of the decision to donate.

"The positive support from my network was invaluable not only to me, personally, but also to my wife, Gail, and two daughters, Amanda and Jessica, who obviously were concerned over my decision to become a kidney donor. And, of course, there were a whole lot of prayers."

The transplant took place at the same place as his father's—Thomas Jefferson University Hospital (where Art's daughters were born). Today, both brothers are doing well.

Art's journeys sparked an idea that would contribute to the genesis of NKF's successful THE BIG ASK: THE BIG GIVE (BABG) platform, which helps kidney patients learn how to find a donor and offers both sides support through sharing their experiences. As a National board member and

Chair, Art helped develop the BABG initiative, which continues to expand across the country, helping thousands of kidney donors like himself, as well as transplant recipients like his father and brother.

Art becoming National Chair represented an exciting development at NKF: He began working with NKF CEO Kevin Longino, a kidney transplant recipient. For the first time, two NKF “customers” were running the organization at the top. As recipient and donor, Kevin and Art represent the two sides of living organ donation and have been an effective team in breaking barriers to transplantation.

“Art’s commitment to NKF’s mission has set an example for us all,” says Kevin. “He’s brought his personal experience, commitment, and ability to every challenge and opportunity. His extraordinary generosity, both financially and with his time, has set a new standard. It’s been a privilege to serve with someone who also knows the issues that patients and families face.” Art has also been a hands-on National Chair, recruiting almost 200

companies for Kidney Walks across the U.S., which help heighten awareness about kidney health.

While transitioning his duties to incoming National Chair John Gerzema, Art will continue to serve on our National Board.

We, your friends at NKF and in the kidney health community thank you, Art!

“Having witnessed firsthand both the significant challenges that kidney disease presented to my loved ones, as well as the life-changing value of kidney donation, I am determined to help reduce the incidence of kidney disease and increase transplantation rates in the U.S.” ▶ Art



NKF National Chair Art Pasquarella and GNY Board Member, Fiona Portington. ▶

# THE PRESIDENT-ELECT WANTS ANSWERS....

As NKF-KDOQI's Vice Chair of Commentaries and Controversies, Holly M. Kramer, MD, MPH, investigates topics that do not have a uniform or simple answer. By putting a spotlight on these large gaps in clinical knowledge, she helps move more funding into kidney disease research. In October, as NKF's new President, Dr. Kramer will rally public attention to the urgent issue of kidney health: "The scientific community and the general U.S. population need to recognize the impact that the kidney disease crisis is having on the U.S. healthcare system. Nephrology remains a specialty with less clinical trials compared to other specialties and we all need to come together to change this—as soon as possible."

Dr. Kramer, a distinguished clinical investigator from Loyola University Medical Center, and Vice Chair of NKF's Kidney Disease Outcomes Quality Initiative (KDOQI), will be assuming leadership from prominent Johns Hopkins nephrologist Michael J. Choi, MD, who has made professional and public education the theme of his term as NKF President.

"I am both honored and energized by this opportunity to serve the people affected by kidney disease, address kidney health issues on a broad scale, advocate for patients, and maintain the high standards of public service set by the National Kidney Foundation," says Dr. Kramer.

Currently an Associate Professor of Public Health Sciences and Medicine in the Division of Nephrology and Hypertension at Loyola, Dr. Kramer's research interests include kidney disease, nutrition, and cardiovascular disease. Long associated with NKF, she is presently a Member of its Scientific Advisory Board as well as Vice Chair of KDOQI Commentaries and Controversies. Previously, she served on the Program Committee of NKF's Spring Clinical Meetings, as Vice Chair of NKF's KDOQI Research Program, and as a Member of NKF's Research Grant Review Committee. In 2016, she was the recipient of NKF's Garabed Eknoyan Award for her key contributions to NKF's KDOQI Guidelines and for clinical research in the field of kidney disease.

"Dr. Kramer's distinguished professional achievements in the area of kidney health, her substantial service to NKF, her dedication and compassion to patients with kidney disease, and her commitment to advancing public awareness of kidney disease will advance our mission to improve the lives of patients with kidney disease," says current President Dr. Michael J. Choi. "I eagerly look forward to her impact on NKF with her research expertise, passion for patient care, and leadership."

Dr. Kramer's career focus has been on the relationship between kidney disease and nutrition, particularly the impact of obesity on kidney health. She received her MD from the Indiana University School of Medicine. After completing a nephrology fellowship at Harvard University Medical School, Dr. Kramer was jointly appointed to the Department of Medicine, Division of Nephrology and Hypertension, and Department of Public Health Sciences at the Loyola University Medical Center. She became Co-director of the Clinical Research Methods and Epidemiology Program, and was later the Program Director for the MPH Program. Dr.

Kramer has also received grant support for her studies of coronary artery risk among young adults and genetics of hypertension in African Americans. She has worked with investigators across the United States and in Jamaica and Africa.

Dr. Kramer was connected to nephrology from the start—her mother was a home training dialysis nurse from the 1970s through the 80s. She even sold candy bars in high school to raise money for NKF of Indiana! "I think I sold about 30 candy bars per day for all four years of high school," she says. She is married to Curt Kramer, who is general counsel of Navistar International, and has two young daughters.

She is a very enthusiastic about the nephrology field—and her patients: "...the best thing about my life, other than my awesome family, is spending my time taking care of patients. Being a healthcare provider for patients with kidney disease is *the* 'rewarding job!'"

We at NKF and the healthcare community, look forward to Dr. Kramer taking the helm and continuing to accelerate public awareness of kidney health—and getting people to eat kidney-healthier.

"I am both honored and energized by this opportunity to serve the people affected by kidney disease, address kidney health issues on a broad scale, advocate for patients, and maintain the high standards of public service set by the National Kidney Foundation." ▶ **Holly M. Kramer, MD**



# INDIVIDUAL SUPPORTERS

Our work would not be possible without the generosity of many individuals, foundations, and corporations who give their time, talent and treasure to support our mission. Their annual contributions fuel our ability to respond to the most urgent need of our community today and their multi-year commitments allow us to invest in solutions for *tomorrow*.

## \$450,000+

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 Patricia Brady Trust  
 Brighthouse Life Financial  
 Tua Burkart Residual Trust  
 Charles and Jo Ann Caldwell Revocable Trust  
 Estate of Winifred Clark  
 Helen Davis Trust

Estate of Edward F. Debard  
 Estate of Helen DeGennaro  
 Deinhart Joint Revocable Trust  
 Thomas D. Dobson Irrevocable Trust (Nate Zolman, Trustee)  
 Estate of David Downs  
 Estate of Joyce Ann Dupraz  
 Estate of Ruth Eberle  
 Jesse Ernest Fesmire Estate  
 Estate of Floyd A. Forman  
 Harriet French Trust  
 Estate of Carole Mae Frizzell  
 Estate of Stephen Gillespie  
 Estate of David Green  
 Claralee Hargrave Charitable Trust

Estate of Cynthia Hembree  
 Estate of DeNelda Jongerius  
 Estate of Nicholas Keeley  
 Barbara Kelly Trust  
 Estate of Col. John Leaphart  
 Estate of Garland and Jacqueline LeRoy  
 Estate of David Liva  
 Estate of Elizabeth Lee Louie  
 Estate of Kathryn Mack  
 Dale G. Marshall and Marilyn J. Marshall Trust  
 Estate of Thomas Marvel  
 Kathryn Marshall McCune Estate  
 Margaret McGaughey  
 Gemmill Trust

Mclver Revocable Trust  
 Estate of Cleveland Meador  
 Estate of Ray A. Medley  
 Estate of Dorothy B. O'Connor  
 Estate of Greta Oswald  
 Estate of Camille Owen  
 Estate of Anne L. Paris Trust  
 Estate of William Poehlman  
 Mary Powell Trust  
 Estate of Dorothy Mae Praegner  
 Bonnie Jean Roike IRA  
 Frances H. Rosser Trust  
 Estate of the Schiller Family  
 Estate of Mary Lou Schirmer  
 Estate of Antonia Schneider  
 Estate of Marjorie Shender

Estate of Donald Skinner  
 Maxine Marie Smith Revocable Trust  
 Estate of Donna Spoonhour  
 Estate of Lonnie Stephens (Garry Campbell, Trustee)  
 Estate of Agnes Swain  
 Estate of Rosemarie Tremonte  
 Albert M. Van Beem Revocable Living Trust  
 Estate of Margaret Welch  
 Tuw W. M. Yeaman Charitable Trust  
 Estate of Mary Eileen Zimmerman

# FOUNDATIONS

## \$10,000+

AEGON Transamerica Foundation  
 Aon Foundation  
 Baltimore Community Foundation  
 Sandra Atlas Bass and Edythe and Sol G. Atlas Fund Inc.  
 BGR Foundation Inc.  
 Boldt Family Fund Inc.  
 Louis and Sandra Berkman Foundation

John, Margo, Andrea and John Jr. Catsimatidis Foundation  
 John and Maurine Cox Foundation  
 GlaxoSmithKline Foundation  
 Stephen A. and Diana L. Goldberg Foundation Inc.  
 John and Marcia Goldman Foundation  
 Grainger Foundation  
 Flora Paxton Hickman Foundation

Highmark Foundation  
 Isaf Family Foundation Inc.  
 ITW Foundation  
 Reva and David Logan Foundation  
 McDowell Longino Charitable Fund  
 McCutchen Foundation  
 John Moffitt Charitable Foundation  
 Merck Foundation

Harvey E. Najim Family Foundation  
 Nismat Foundation Inc.  
 Nokomis Fund  
 OneLegacy Foundation  
 PA Department of Health, Bureau of Family Health  
 Arthur and Gail Pasquarella Family Foundation  
 Rees-Jones Foundation  
 Research Foundation of SUNY

Kenneth L. and Eva S. Smith Foundation  
 Wawa Foundation Inc.  
 Wasserman Foundation

**Mission Statement** The National Kidney Foundation, a major voluntary nonprofit health organization, is dedicated to preventing kidney and urinary tract diseases, improving the health and well-being of individuals and families affected by kidney disease, and increasing the availability of all organs for transplantation.

# FY19: LOOKING FORWARD

## Already on the Move!

NKF is leading off FY19 by opening a new era and new possibilities. We believe that current advances in medical science are making a cure for kidney disease an achievable goal within our reach. Therefore, one of our **new long-term objectives is facilitating and expediting a cure for kidney disease**. This reaches back to our roots and will be a fulfillment of the dream of our founder Ada DeBold, who began the foundation seeking a cure for her son. This exciting development was brought about by advances in technology that will allow

us to build the first national CKD patient registry. This **new NKF CKD patient registry will create a unique interactive community of patients throughout the continuum of CKD** that links patients' reports on their health status, priorities, and activities with objective data from electronic health records. For the first time, sponsors and investigators will be able to access a large and diverse group of CKD patients for clinical trial recruitment, and for **new insights into what causes and prevents progression of kidney disease**.

### Advocacy

In FY19, NKF also continues as a **voice for patients and families on Capitol Hill**. NKF will continue its leadership in the kidney disease aspect of the **Million Hearts campaign**, an initiative co-led by the Centers for Disease Control and Prevention (CDC) and the Centers for Medicare and Medicaid Services (CMS) to reduce heart attacks and strokes by one million episodes by 2022. NKF discussions with the Department of Health and Human Services (HHS) resulted in the inclusion of CKD into Million Hearts. We will also continue advocate passage of the **Living Donor Protection Act (H.R. 1270)** to provide protections for living organ donors and help remove barriers to living donation.

### Living Donation

**THE BIG ASK: THE BIG GIVE** in-person **trainings** with transplant centers will continue to expand across the country, giving patients and families the tools they need to find a living kidney donor. Also planned is a pilot online

virtual training to increase the reach of this lifesaving initiative to a much wider audience.

### Education and Research

**Two major KDOQI Guideline updates:**

***KDOQI Clinical Practice Guideline for Nutrition in CKD***: KDOQI, in collaboration with the Academy of Nutrition and Dietetics, is updating its nutrition guideline. Nutrition is a key consideration in minimizing the progression of kidney disease and associated complications.

***KDOQI Clinical Practice Guideline for Vascular Access—Update***: The last revision of this guideline was completed 10 years ago. Changes in patient demographics and increasing patient longevity, as well as a growing body of literature on improved ESRD care, have renewed interest in access management.

NKF is continuing its partnership with the **Patient-Centered Outcomes Research Institute** with the **New**

**PCORI Peers project “Comparing the Effectiveness of House Calls and Peer Mentorship to Reduce Racial Disparities in Live Donor Kidney Transplantation.”** NKF will also be hosting the **NKF Controversies Conference on CKD and Children** and the **second part of the KDOQI Home Dialysis Controversies Conference**. (See page 9.)

### CKDintercept

NKF's earliest detection initiative continues to launch and expand programs under its strategy, including the **American Society of Clinical Pathology (ASCP) Registry Proposal**. ASCP is developing a national registry to gather data from all the major testing laboratories in the U.S. NKF submitted a proposal for CKD testing data to be included. Should this program move forward, a **national benchmark to CKD testing will be established**. **CKDintercept's Laboratory Engagement Plan** is recruiting smaller, regional laboratories into the

program and **promoting the availability of the “Kidney Profile.”** (See page 5.) NKF will be launching and testing **CKDintercept's CKD Change Package**, developed in collaboration with Harvard, Cleveland Clinic, Lehigh Valley Health Network, UCSF, Henry Ford Health System, the Indian Health System, and Geisinger. The Change Package is a document outlining how a primary care practice, FQHC, or health network can **implement a population health strategy for CKD in their institution**.

### Patients and Families

**Improving the lives of patients and families is central to what we do—helping people.** To that end, NKF patient services just launched a **new online community, Parents of Children with Kidney Disease**, and will be launching a **New NKF Peers app** which will allow mentees to **self-select mentors and also communicate with multiple mentors in a community forum**.





National  
Kidney  
Foundation®

30 East 33 Street  
New York, NY 10016  
[Kidney.org](http://Kidney.org)



Fueled by passion and urgency, NKF is a lifeline for all people affected by kidney disease. As pioneers of scientific research and innovation, NKF focuses on the whole patient through the lens of kidney health. Relentless in our work, we enhance lives through **action, education, and accelerating change.**