

### [FOCUSED]



National Kidney Foundation®

**Curtis** Kidney Recipient

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"I swim, bike ride, go to the beach, walk our dogs, all hand-in-hand with my husband, something that would not have been possible without THE BIG ASK: THE BIG GIVE and the entire group of local and National NKF staff."

Cindy Stein, living donor kidney recipient of Cranberry Township, PA



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# **CAMESSAGE FROM LEADERSHIP**

**Kidney disease is a worldwide health crisis**. In the United States, an estimated 37 million people may have chronic kidney disease (CKD). The majority don't know they have the life-threatening illness. Symptoms often don't appear until the end stages, when it is most deadly, less treatable, and overwhelming. Furthermore, 1 in 3 American adults are at risk for kidney disease.

To make this urgent health crisis even more challenging, there is no one cause of kidney disease or kidney failure. The disease is as complex as the lives patients must live after diagnosis.

Too little time and public funds are spent on understanding CKD and improving lives of patients. And yet, too much public money is spent treating it.

#### That's where we come in.

We are focused on:

- eliminating all preventable CKD;
- making transplants available to all patients who want one;
- relentlessly advocating for a better quality of life and outcomes for all kidney patients.

We raise funds so we can invest in research, patient programs, professional education, public awareness, and legislative and regulatory reform.

The National Kidney Foundation (NKF) has been working diligently for patients for nearly 70 years, and we are still at it. We are forever moving our goalpost forward to the next steps in lessening the impact for the millions who suffer with kidney disease. We are constantly adding to our diverse catalog of initiatives — because when we see a problem, we want to find a solution. We know that we are not going at this crisis alone, but we are leaders in the effort to fight kidney disease.

Within these pages, you will get a snapshot of what was new in FY19, just some of what's ongoing and what we could do if we had the resources.

**We will never give up** trying to find ways to prevent CKD, lessen the burden for patients, increase transplantations, educate the public and healthcare professionals, and stop the progression of this powerful disease. We hope that you will join us in this effort.

#### Sincerely,

John Gerzema, NKF Chair of the Board Holly Kramer, MD, MPH, NKF President Kevin Longino, NKF Chief Executive Officer 66

"We have a public health crisis that isn't being addressed and millions of people need us to find the ways to eliminate all preventable chronic kidney disease."

John Gerzema, NKF Chair of the Board

"NKF's focus on patients is critical for those people carrying the burden of dialysis and late-stage CKD." Holly Kramer, MD, MPH, NKF President

### INTRODUCING THE NKF BOARD

Year after year, each class of the NKF Board of Directors have served with a personal connection to kidney disease.

### Manish Agarwal, President and COO Attain LLC, McLean, VA

Personal connection: Mr. Agarwal is a transplant recipient and is passionate about kidney health, and actively serves NKF Serving the National Capital Area as Chair of the Board.

Thomas P. Cassese, Vice President Hydroflow Barnes Division, Chapin, SC Personal connection: Mr. Cassese has served on the local NKF Serving the Carolinas—South Carolina Board since 1988, and on the National Board since 2014. More than 20 years ago, he was approached by a close friend with CKD to help fund-raise for NKF.

#### $\textbf{Michael J. Choi,} \, \mathsf{MD}$

Chief of Nephrology, Georgetown University School of Medicine, Washington, D.C.

**Personal connection:** Dr. Choi's uncle is on dialysis and his father-in-law has had a kidney transplant.

#### Matthew Cooper, MD

Director Kidney and Pancreas Transplantation, Medstar Georgetown Transplant Institute (MGTI) Professor of Surgery, Georgetown University School of Medicine, Washington, D.C.

**Personal connection:** Dr. Cooper's work with NKF is centered on improving the lives of people with CKD and supporting the need for organ transplantation for those with ESKD.

**Joseph Cosgrove** Chairman, President and CEO Pentec Health, Inc., Boothwyn, PA Personal connection: Mr. Cosgrove's mother-in-law and his best friend have received a diagnosis of CKD.

**Jennifer DaSilva**, President Berlin Cameron, New York

Personal connection: Ms. DaSilva knows that awareness is just part of the battle against the progression of kidney disease, so she is driven in her efforts to help spread NKF's messages.

John T. Gerzema, NKF Chair CEO, Harris Insights & Analytics, New York

Personal connection: Mr. Gerzema experienced kidney damage as a child.

**Brennan Hart**, Esq. Pietragallo, Gordon, Alfano. Bosick, & Raspanti, LLP, Pittsburgh

**Personal connection:** Mr. Hart donated a kidney to his child 20 years ago.

**Tom Hough,** Financial Consultant Board Member Bain Capital Specialty Finance Plano, TX

Personal connection: His daughter received her first diagnosis of kidney stones at age 9. He joined the local NKF board to learn more about kidney disease and to help others deal with kidney disease.

Kailesh Karavadra, Managing Principal Ernst & Young LLP, San Jose, CA

**Personal connection:** His mother was a living donor for her sister, who ultimately lost her life to kidney disease.

#### Kevin Longino, CEO

National Kidney Foundation, New York Personal connection: He is a kidney transplant recipient, and son and grandson of kidney patients.

**Samuel J. Marchio**, Regional Vice President, Federal Affairs, Head of Congressional Affairs Anthem, Inc., Washington, D.C.

**Personal connection:** He is passionate about kidney health, public health, and fundraising

Holly Kramer, MD, MPH NKF President Loyola University, Chicago

Personal connection: She is a second-generation kidney healthcare professional, dedicating her life to improving outcomes for people with this disease.

Art Pasquarella, CRE, EVP/COO Equus Capital Partners, Ltd., Philadelphia Personal connection: He is a living donor, and two of his immediate family members have received kidney transplants.

**Stephen Pastan**, MD, Associate Professor of Medicine, Emory Transplant Center, Atlanta

**Gregory W. Scott**, President Winfield Management Point Pleasant, PA

Personal connection: Mr. Scott donated a kidney to his son.

#### Michael J. Stevenson,

CPA, NKF Secretary Partner, Clarus Partners, Columbus, OH

Personal connection: After his diagnosis of glomerulonephritis, Mr. Stevenson received a kidney from his brother, Jim, in 1996, and has been a champion of trying to raise awareness about CKD and ultimately trying to find a cure.

**Stephanie Stewart,** LICSW, MBA, Operations Administrator Neurosciences and Post Acute Care, Mayo Clinic, Mankato, MN

Personal connection: Ms. Stewart cares about improving the lives of people with CKD. Many of the individuals, mostly patients, with whom she has worked with have touched her life in very personal ways.

Anthony Tuggle, Vice President Mobility Sales and Service, AT&T, Atlanta Personal connection: A 20-year kidney transplant recipient, Mr. Tuggle is committed to working with NKF towards kidney disease prevention efforts.

Bradley A. Warady, MD

Children's Mercy Hospitals & Clinics, Pediatric Nephrology, Kansas City, MO

Personal connection: Dr. Warady has taken advantage of his opportunity as an NKF Board Member to do what he has done throughout his career: advocate for children affected by kidney disease. "We dream of a future

where there is no longer a need for a waitlist because everyone who wants a kidney will get one."

Kevin Longino, NKF Chief Executive Officer and kidney recipient





### Kidney .**TIENT** Summit

### NATIONAL STAFF

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**Elizabeth Montgomery** Vice President Learning Strategies and Primary Care Programs

**Troy Zimmerman** Vice President Government Relations

# **OKIDNEY DISEASE** AT A GLANCE

### 37 MILLION American adults have CKD

1 IN 3 American adults are

at risk of CKD

**35%** of all patients treated with dialysis are African American

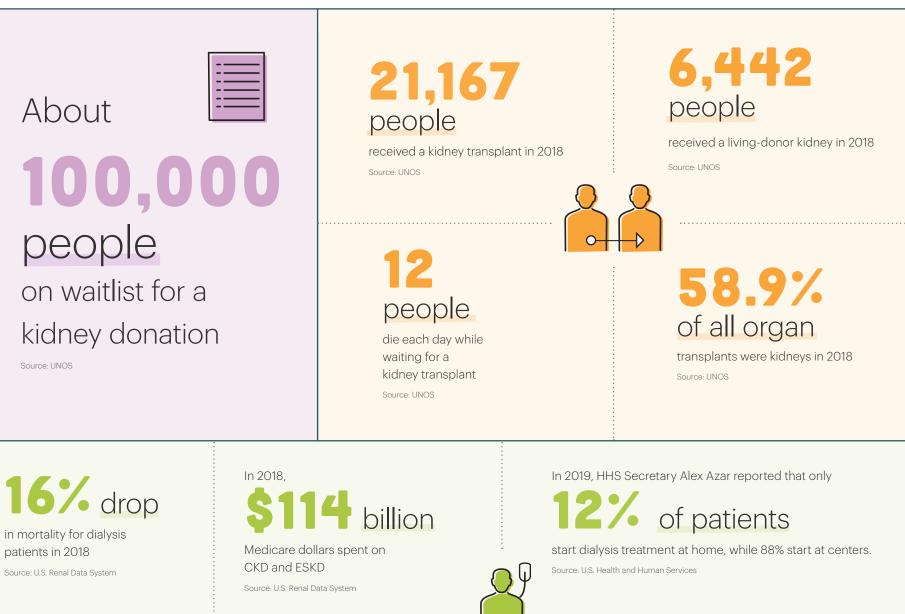
Source: U.S. Renal Data System

### AFRICAN AMERICANS

suffer from kidney failure 3 times more than White Americans.

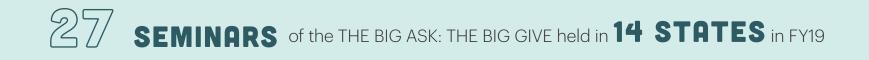
**HISPANICS** are 1.3 times more likely to develop kidney failure than non-Hispanics.

### **KIDNEY DISEASE BY THE NUMBERS**



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### **NKF STATS** AT A GLANCE







co-sponsor Living Donor Protection Act of 2019

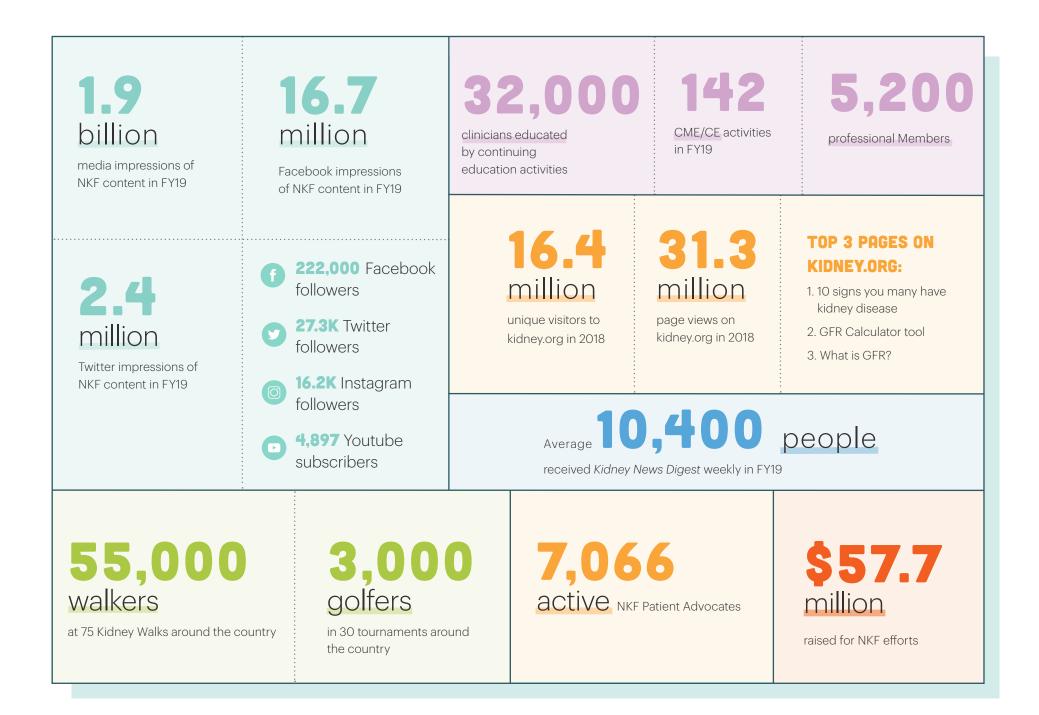
### 105 ADVOCATES

representing 43 states attend 2019 Kidney Patient Summit in Washington, D.C.

### 5 PEER-REVIEWED JOURNALS

published by NKF

Source: National Kidney Foundation



# O BAVANCING KIDNEY TRANSPLANTATION

NKF is committed to the vision that everyone who wants a kidney transplant should have access to one. No cost impediments. No donor discrimination. No barriers whatsoever. Listed here are just some of the ways we are advancing that goal. This past year, we held **27 in-person trainings for THE BIG ASK: THE BIG GIVE in 14 states**, where we taught hundreds of kidney patients how to raise their hands and let their friends and family know they need a kidney. So far, we have early promising results and high hopes. In one of the first trainings, we saw a dramatic jump in potential living donors.

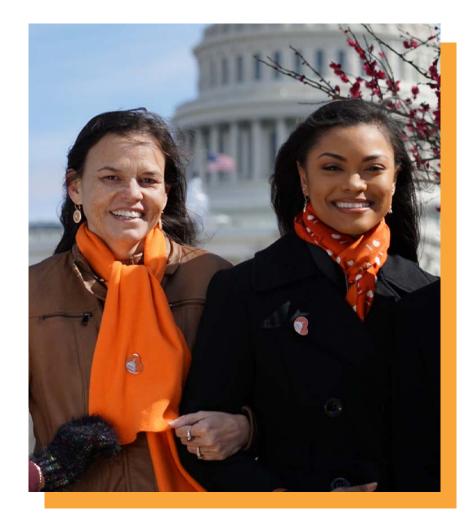
We set out to reach a previously underserved segment of the kidney disease population when we launched **THE BIG ASK: THE BIG GIVE PSA series in Spanish**. In FY19, the series received more than **154 million media impressions** in broadcast, print, and online platforms.

We released the Report of the National Kidney Foundation Consensus Conference to Decrease Kidney Discards, which was the result of a year-long effort with leading transplantation experts in the U.S. **devoted to solving the kidney utilization**  problem. The team came up with 14 recommendations that should be implemented to reduce the number of kidneys retrieved from deceased donors that are ultimately never transplanted.

This past year, we again successfully advocated for state and national **legislation to protect living donors**. (For more information, please go to the section "Changing Laws and Influencing Minds.")

NKF worked closely with the California company CareDX to ensure **paid leave for their employees who become living donors**. They are one of the first U.S. corporations that implemented a policy that will help those who want to donate an organ by making it easier financially and removing the fear of losing wages or their jobs.

NKF reached almost 20,000 patients through the NKF Cares patient help line and NKF Peers mentoring program in FY19.





"We have thousands of people on the transplantation waiting list. It can take up to five years to even move up that list. We need more people who are willing to be living donors. You only need one kidney to live and it only takes one to make someone else's life much better."

Rahmeka Cox, above, right, Miss New York, who is the daughter of a living donor transplant recipient



### DREAMS FOR BETTER LIVES

NKF is always looking toward the future with simple, aspirational goals. We asked our team, "**What could we do**" if we had unlimited resources?

- Create a virtual version of our THE BIG ASK: THE BIG GIVE in-person training;
- Create a "Basics" workshop to teach patients who haven't yet been added to the kidney waitlist and their families about living donation and transplantation because our current program only focuses on patients on a waitlist through transplant centers;
- Test a program to **connect trained social workers with patients** who've joined a BABG training to support them until they get a kidney;
- Implement the recommendations of the NKF Consensus Conference to Decrease Kidney Discards to reduce the number of unused donated kidneys, and increase transplants.

# **OFFECTIVE OFFECTIVE OFFEC**

No child should suffer from chronic kidney disease (CKD) and no parent should have to watch their child struggle with the challenges CKD and end-stage kidney disease (ESKD) bring. In 2017, almost 5,700 children had ESKD, according to the U.S. Centers for Disease Control and Prevention. We are devoted to families of children with CKD and kidney failure, and those who are at risk, and lessening the burdens they face every day. Here are some of our efforts over this past year that give families hope:

In FY19, we started the **online forum Parents of Children with Kidney Disease**. Nearly 300 families have already joined and now help each other navigate through the challenges of parenting a child with CKD.

In December, we did what we do best, **we gathered** children with CKD, their parents, and **the experts** in pediatric nephrology from around the world for the *NKF Scientific Workshop* on Chronic Kidney Disease in Children in Atlanta. This was a landmark workshop on pediatric nephrology. Participants shared their knowledge and unique experiences in smaller groups during the conference.

The NKF team will use the results of this workshop to:

1. **publish** recommendations for improving care of pediatric CKD patients; 2. **survey** the pediatric CKD community to determine the needs of patients and their care partners/ parents; and

3. **create** an NKF educational initiative on pediatric CKD for patients, parents, and clinicians.

Also, NKF created and now offers a **special version of "THE BIG ASK: THE BIG GIVE"** in-person trainings just **for parents** trying to find a living donor for their children.

NKF is partnering with the American Academy of Pediatrics and the American Society of Pediatric Nephrology to **develop educational content for CKD patients, their parents, and caregivers**, as well as those at risk.

This collaboration reflects NKF's effort to put a stake in the ground against pediatric CKD. The materials will be posted on kidney.org.

Face painting at Kidney Walk



"Well-controlled clinical trials in children with CKD are scarce. The time is right to make every effort to enhance the care of children with CKD."

66

**Bradley A. Warady**, MD, Director, Division of Nephrology, Children's Mercy Kansas City, and Professor of Pediatrics University of Missouri – Kansas City School of Medicine

#### DREAMS FOR BETTER LIVES

There is so much that can be done for children with CKD. Here are just a few of our team's dreams for the future to better the lives of children with CKD:

**Compile a comprehensive manual on kidney disease for parents and patients:** Understanding and Navigating Pediatric Chronic Kidney Disease:

- Deliver through: print, webinars, Facebook Live, videos, apps, and all other forms of media;
- Include unique coloring books, board games, educational kidney toys/models;
- Develop medical information specifically on pediatric kidney diseases;
- Address psycho-social aspects of the disease, such as:
  - How to tell friends and others about the disease
  - What to expect: how life might change
  - Bullying
  - How to get help for social workers, psychologists;
- How to deal with school administrations about:
- Medicines
- Individualized Education Programs (IEP) and extra help
- Missed days
- Teachers;
- Dietary aspects of the disease;

- How to interact with doctors and advocate on behalf of the child;
- Handling insurance;
- How to prioritize all the information coming from doctors; and
- Transitioning to adult care.

Implement the recommendations of the NKF Consensus Conference to Decrease Kidney Discards to **reduce the number of unused donated kidneys**, which would increase the number transplanted.

National and regional **conferences for parents** of kids with CKD.

National and regional **conferences for** kids with CKD.

#### Day and sleep-over camps for kids with CKD.

**Health-checks for at-risk kids** that include tests for kidney function, blood pressure, obesity, and poor nutrition status.

Create educational programs about kidney health and disease to **promote prevention**.

Advocate for federal laws and policies to increase pediatric nephrology trials.

# **CARTENESS AWARENESS FOR ALL**

NKF continues to be the authoritative voice raising awareness about CKD, a disease the vast majority of affected Americans don't know they have. In FY19, our informational pages, social posts, online guides, and expansive media coverage were seen nearly
1.9 billion times, and more than
16.4 million unique visitors hit the NKF website looking for information and support.

Not only have we increased our presence across all media with more relevant coverage and social posts than ever before, our engagement is rising, too. More and more people are reaching out to us through social media. Transplant anniversaries and living donation stories continue to be an important content strategy that receives incredible engagement of **150 to 200 percent above average** of all other NKF content.

During National Kidney Month, NKF partnered again with **Pro Football Hall-of-Famer Jerry Rice** for two PSAs titled *Kidney Stats* and *Invincible*, which premiered in March and will continue to air all year. So far, these **PSAs** garnered 26.2 million impressions and added to our overall **National Kidney Month coverage of 622** million impressions, up more than **30 percent** from 460 million in the previous year.

In FY19, NKF named, for the second time, television personality and **singing powerhouse, 11-year-old Angelica Hale as NKF's Kid Ambassador**. She promotes the importance of living donation and kidney health for all and she has helped NKF achieve **439 million impressions in coverage**  related to her work with us. In FY19, her special kid-to-kid PSA detailing her struggles with kidney disease was the **winner of the Sharecare Award** for Public and Community Health/Policy. The Sharecare Award is presented in association with The National Academy of Television Arts & Sciences, New York Chapter, which fosters creativity and inspires artistic and technical excellence through the renowned Emmy Award.

In March, Angelica joined advocates at the Kidney Patient Summit in Washington, D.C., in March and wowed members of U.S. Congress with her adult-like poise and expertise. Angelica appeared on television programs Good Day DC, ABC 7 Good Morning Washington, and NBC News *Washington* to promote the Kidney Patient Summit, and performed live at NKF's "2019 World Kidney Day Congressional Reception," which was also shared with her millions of followers on Facebook. Special media coverage of HHS Secretary Alex Azar's speech to advocates at the Summit yielded an impressive 133 million impressions.

NKF has forged a special relationship with the social media giant Facebook. We were invited to the "Facebook Community Summit" in San Francisco for a national roundtable on how Facebook can help nonprofits. We have also been asked to provide feedback on their beta-mode tools for nonprofits. In FY19, our Facebook fundraising campaign generated an estimated \$1.8 million. We are excited about how much more we can use this media platform to increase funds and awareness. Stay tuned for more developments. For the first time in NKF's history, we asked a **dozen social media influencers** to amplify our message by creating their own posts about kidney health.





"I am so excited to be a host of the livestream for NKF. I'm hoping everyone will make a contribution to a cause I truly believe in and can definitely relate to—helping people with kidney disease."

Angelica Hale, NKF's Kid Ambassador and television star



"When my brother, Tom, was diagnosed with CKD, that was the heaviest hit of all. I want to make kidney stats as widely quoted as football stats."

66

Jerry Rice, Pro Football Hall-of-Famer and kidney advocate

### DREAMS FOR BETTER LIVES

Most people walking around today with CKD do not know they have this dangerous disease. We want to change that and make sure everyone with CKD is aware and knows what to do to have a quality life with this disease.

# **OMAKING LIVES** BETTER RESEARCH

We wear many hats at the National Kidney Foundation and have played many important roles over the last seven decades. We are a patient advocacy organization, a society of kidney health professionals, and we support research and education in the field of nephrology. Without our work, many innovations would never have been developed. In FY19, some of the ways that NKF has worked to make lives better include the following highlights:

### We are laying the groundwork to **increase the rate of diagnosis** of

CKD with The Laboratory Engagement Initiative, which promotes the widespread use of two biomarker tests to evaluate kidney function, through the "Kidney Profile." NKF first introduced the Kidney Profile in FY18. We have focused our efforts this year to make the Kidney Profile commonly used nationwide. The Kidney Profile was recently included in the influential *Choosing Wisely® Initiative* to be **the optimal test for kidney disease** among Americans with diabetes and/or hypertension.

A report co-authored by NKF President Holly Kramer, MD, MPH, in the Journal of the Academy of Nutrition and Dietetics – titled "Medical Nutrition Therapy for Patients with Non-Dialysis-Dependent Chronic Kidney Disease: Barriers and Solutions," showed that **90** percent of these CKD patients never meet with a dietitian, something that needs to change.

NKF is partnering with Tufts University on a new three-year PCORI grant "Promoting Autonomy and Improving Shared Decision Making for Older Adults with Advanced Kidney Disease," to help older patients with advancedstage kidney disease and their family care partners make decisions that best reflect their goals and preferences for care.

For the first time, **NKF received a major grant** from the U.S. Veterans Administration Center for Innovation to refine and study our web-based kidney education tool that helps veterans and others to understand kidney disease risk and what can be done about it. For example, a teach-back video will be produced to help foster patient-clinician discussions about kidney disease. Tools like this are designed to promote kidney disease awareness, diagnosis, and enhanced treatment.

NKF, Geisinger, and Healthy.io announced promising results after the initial rollout of a **study using a smartphone-enabled home urinalysis device**, which helps improve diagnosis.

The second KDOQI Home Dialysis Conference was held in December. A group of more than 70 clinicians, researchers, policy makers, patients, care partners, and industry representatives gathered to launch the "Home Dialysis Quality Improvement Initiative," a major, multi-disciplinary effort that we hope will result in moving more and more patients out of treatment centers and into home dialysis.

In partnership with the Alport Syndrome Foundation, NKF hosted its second Externally Led Patient-Focused Drug Development Meeting, this time on Alport syndrome. These meetings bring together patients and their care partners, representatives from the U.S. Food and Drug Administration, pharmaceutical companies, and other stakeholders, all to hear patients' experiences living with the disease. The *Voice of the Patient Report*, a summary of the meeting, will be submitted to the FDA. It is an important step to **advancing the development of better therapeutic drugs** with fewer side effects.





"We are facilitating innovations in kidney healthcare every time we train a new kidney professional or spend a dollar on a new research investigation."

Holly Kramer, MD, MPH, NKF President

### YOUNG INVESTIGATOR AWARDS

#### The 2018 Research Grant Recipients of the NKF Young Investigator Awards

### Sometimes the best ideas come from the youngest scientists, but they

don't always have a leg up in securing funding for their research. That is why years ago we began the Young Investigator Awards to inspire young scientists to not only study nephrology, but also to innovate within the field.

#### We were honored to support five young scientists in FY19 with one-year grants to dive into their unique clinical investigations.

The recipients in FY19:

- Kevin Erickson, MD, MS, was awarded a Young Investigator Award to further examine whether receiving regular nephrology care prior to developing end-stage kidney disease helps patients remain employed. Dr. Erickson is an Assistant Professor of Medicine–Nephrology, Baylor College of Medicine in Houston.
- Syed Ali Husain, MD, MPH, was awarded a Young Investigator Award for research to save more lives by using more kidneys from deceased donors through improving the quality assessment of organs. Dr. Husain is an Assistant Professor of Medicine at the Columbia University Medical Center, and an Associate Director of the Renal Fellowship there.
- Daphne H. Knicely, MD, received the Young Investigator Award to spearhead a vital program that seeks to sharply increase health literacy among patients who have CKD. She is Associate Director, The Johns Hopkins Nephrology Fellowship Training, and an Assistant Professor of Medicine at the University's School of Medicine.
- Jennifer Scherer, MD, was awarded the Young Investigator Award for a pilot study testing whether palliative care integrated with nephrology care improves quality of life. Dr.
   Scherer is an Assistant Professor at the Department of Medicine, NYU Langone Health.
- Roderick Tan, MD, PhD, was awarded the Edith H. Blattner Young Investigator Grant for research that will utilize high-resolution ultrasound to closely examine the kidney's vital small blood vessels, which he hopes will give doctors a better indicator of kidney function and patients a chance of recovery after injury. Dr. Tan is an Assistant Professor of Medicine, Division of Renal-Electrolyte, Department of Medicine at the University of Pittsburgh.



Young Investigator Award presentation

### DREAMS FOR BETTER LIVES

- We always dream of innovative ways to help patients and their family members live their best lives. We want to see more and more patients achieve this **by moving toward home dialysis for those patients who qualify.**
- We would focus more support **toward efforts to develop new or improved therapeutic drugs**, with fewer side effects, that lead to better outcomes for patients.

# **OZHANGING LAWS AND INFLUENCING MINDS**

Patients, healthcare professionals, legislators, and policy shapers have been coming together to serve patients with chronic kidney disease since the earliest days of NKF. Voices of the many continue to make the biggest impact on our nation's policies that affect people with kidney disease. Here are some of FY19 highlights in changing laws and influencing minds. We came out against California's **Prop 8 in FY19 and it was defeated by the electorate**. It was bad for dialysis patients because it would have had the unintended consequence of making dialysis centers in rural and impoverished communities unaffordable, and it would have reduced access to care.

Getting the federal Living Donor Protection Act (S. 511 in the U.S. Senate and H.R. 1224 in the House) signed into law is a top priority for NKF. In February, Sen. Kirsten Gillibrand (D-NY), Sen. Tom Cotton (R-AR),

Rep. Jerry Nadler (D-NY) and Rep. Jaime Herrera Beutler (R-WA) came together to introduce the legislation. As of publication, there are dozens of bipartisan co-sponsors of the bills in both the House and the Senate. NKF advocates are working hard to build support in Congress for this federal law that would protect living organ donors from various insurance discrimination. The bill would also codify into law an August 2018 U.S. Department of Labor opinion letter that living donation is covered under the Family and Medical Leave Act. which protects a donor's employment during the recovery from surgery (NKF worked closely with Rep. Beutler to obtain clarification that resulted in the department's letter).

Though we are working to get this federal legislation passed, NKF's Kidney Patient Advocates, local volunteer leaders, and the local staff are **leading the charge to improve kidney and**  transplant policies state by state. Idaho, Maine, and New York became the first states to pass these protections in 2018. They were followed in 2019 by Arkansas, Kansas, Maryland, Colorado, Arizona, Oregon, Illinois and Oklahoma. More states could pass similar laws in the coming years.

In 2018, NKF helped pass legislation for paid leave for living donors in Colorado.

For the first time, **U.S. Health and Human Services Secretary Alex Azar**, who is the son of a kidney transplant patient, spoke to more than 100 patient advocates gathered together in Washington, D.C., at the Kidney Patient Summit and explained **his vision for transforming kidney care.** 

Former NKF Board Member Jeffrey S. Berns, MD, co-authored an editorial for the Journal of the American Society of Nephrology titled "Addressing Financial Disincentives to Improve CKD Care," which **called for Medicare reform**.

NKF, in conjunction with the "Million Hearts" initiative by the Centers for Disease Control and Prevention (CDC) and the Centers for Medicare and Medicaid Services (CMS) released a comprehensive report Chronic Kidney Disease Change Package: Population **Health Strategies** for Cardiovascular and Kidney Disease Risk Reduction for clinicians and public health practitioners. Years of work by NKF's dedicated team of advocates, volunteers and staff championing the **need for reforms to CMS payments** and in 2019, have paid off with a sweeping a **Presidential Executive Order** in July (which falls in NKF's FY20) that will change the way patients are treated by shifting financial incentives to increase both deceased donor and living donor transplants; incentivize home dialysis; and focus on prevention. We will have more updates in the FY20 Annual Report.





"We have the technology to revolutionize the lives of American kidney patients. We've waited long enough. We just need renewed ambition and new polices. We are committed. Together, we can deliver much better care and longer lives for Americans with kidney disease."

> Alex Azar, HHS Secretary, told advocates at the NKF Kidney Patient Summit, March 4





### DREAMS FOR BETTER LIVES

- We want to build a strong **grassroots group of advocates** in each of the 435 U.S. congressional districts to fight for kidney patient protections, reform, and build support for public policies.
- We envision a world where there are no financial barriers to living organ donation. Living donation must be cost neutral, donors should not suffer economic loss for giving an organ, nor should they have financial gain. We want to end employment discrimination and lost wages. All non-medical expenses related to donation, such as travel, childcare, and dependent care, as well as follow-up medical care related to donation, should be covered on behalf of the living donor.
- We will fight for **better public policy that improves early detection and management** of chronic kidney disease that helps to prolong kidney function. We will continue to work with Congress and the Administration to give patients choices in their kidney replacement therapy that best fits their lifestyles, including in-center dialysis, all forms of home dialysis, or kidney transplantation.

2019 Kidney Patient Summit in Washington, D.C.

# **CAIDING THE PROFESSIONALS**

NKF has long championed kidney healthcare professional training and ongoing continuing medical education on kidney disease. For nearly seven decades, NKF has been bringing professionals together to share their experiences and latest research. Listed here are the highlights of these efforts in FY19. NKF has offered more than 142 CME/ CE accredited programs, locally, nationally, and online, **to more than 32,000 kidney professionals**.

This past year, we added new, exciting features to our annual NKF Spring Clinical Meetings, the leading nephrology conference in the country. It drew nearly 3,000 healthcare professionals, and hundreds of studies and trials were presented. **We livestreamed 10 sessions for those who couldn't attend the popular event**, and we included the offering of interprofessional Continuing Education credits.

We launched a webinar training program in partnership with TMF Health Quality Institute titled *Guide* to Detecting and Delaying Progress of Chronic Kidney Disease, featuring NKF Past President Michael Choi, MD.

This year, NKF launched a new medical, peer-reviewed, **open-access journal** called *Kidney Medicine*. The mission of *Kidney Medicine* is to disseminate knowledge relevant to the care of people with or at risk of kidney disease. All published research is freely available to clinicians, researchers, patients, and care partners.

NKF partnered with the American Journal of Kidney Diseases to offer CME credit for NephMadness, **a free educational initiative** that is modeled after the annual college basketball tournament, with 32 nephrology concepts "competing" in eight regions. More than 1,000 physicians participated in 2018.

We also launched a new national program, **Renal Roundtables**, a series of locally based educational events that allow for the sharing of case studies, common experiences, and best practices. The program is **also aimed at building collaborative practice in local communities**, and provides a more participatory, cooperative, and coordinated approach to shared decision making around health issues.

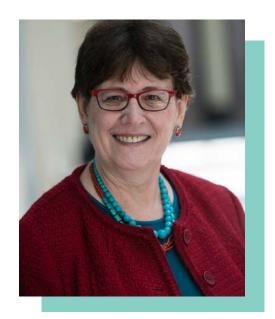
The NKF Education Committee launched the *Life as a Nephrologist podcast* series, which explores what day-to-day life is like for nephrologists at different points in their careers. Fellows, residents, and medical students learn why the field of nephrology is exciting, why it's challenging, and why we hope more physicians will pursue nephrology as a specialty.

NKF **launched Nephrology Essentials**—an online synopsis of peer-reviewed, guideline-driven educational series developed by the NKF Council of Advanced

Practitioners to address management of kidney patients.

The Council on Renal Nutrition developed a **database of dietitians** who treat pre-dialysis CKD patients, an underserved population. The Council of Nephrology Social Workers conducted a **salary and caseload survey**. The results were published in the *Journal of Nephrology Social Work* (Vol. 42, Issue 1).

The Council of Nephrology Nurses and Technicians partnered with the Nephrology Nursing Certification Commission to launch the CNNT Nurse Mobility Scholarship program, which offers up to three **\$3,000 scholarships to assist nurses** in their pursuit of higher education in nephrology nursing.

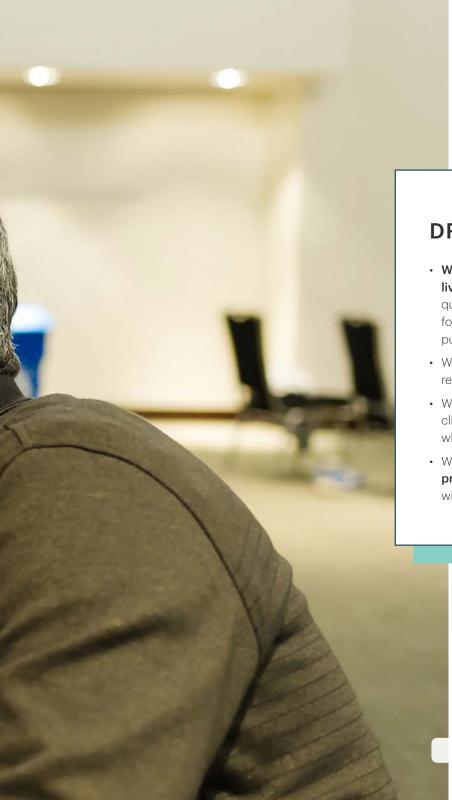


### 66

"I love being a lifelong member of NKF because it's multidisciplinary and patient inclusive."

Katy Wilkens, MS, RD





### **DREAMS FOR BETTER LIVES**

- We will never stop supporting those who have dedicated their lives to kidney disease. Their work is just too important in our quest to change the lives of patients. We know that more programs for professionals is the pathway to better outcomes. Look for more publications for professionals from NKF.
- We dream of **developing a mentor program** for medical students and residents considering the field of nephrology.
- We dream of creating a KDOQI **smartphone app** to make all of our clinical practice guidelines available to practitioners wherever they are, whenever they need help deciding on the best treatment for a patient.
- We will continue to **support the full spectrum of healthcare professionals** to realize our dream that all people with kidney disease will live better and longer.

NKF Spring Clinical Meetings

## OPPROFILE OF CORPORATE CHAMPION

Otsuka Pharmaceutical Company, Ltd. was selected to receive the 2019 Corporate Innovator Award from the National Kidney Foundation at the 2019 Spring Clinical Meetings in Boston. In April 2018, Otsuka's JYNARQUE® (tolvaptan) was approved by the U.S. Food and Drug Administration (FDA) as the first treatment to slow kidney function decline in adults at risk of rapidly progressing Autosomal Dominant Polycystic Kidney Disease (ADPKD).

"ADPKD is the most commonly inherited kidney disorder, and it affects all races and ethnic groups equally," said Kevin Longino, CEO, National Kidney Foundation and a kidney transplant recipient. "**The Corporate Innovator Award** recognizes Otsuka's significant contribution to improving the lives of people with ADPKD and we congratulate them on this achievement."

ADPKD is diagnosed in about 140,000 people in the U.S., and impacts families across multiple generations, since a parent with ADPKD has a 50 percent chance of passing the disease to their children. ADPKD is a genetic disease with consequences that can lead to dialysis or kidney transplantation. It is a progressively debilitating and often painful disorder in which fluid-filled cysts develop in the kidneys over time. These cysts enlarge the kidneys and impair their ability to function normally, leading to kidney failure in most patients.

"Otsuka is honored to be recognized by the National Kidney Foundation as a recipient of the Corporate Innovator Award," said Louis Allesandrine, VP Oncology and Renal Sales and Marketing. "Since the FDA approval of JYNARQUE one year ago, many people living with ADPKD in the U.S. have received this treatment. Otsuka continues to make significant investments in our nephrology research and development, and is committed to meeting the long-term unmet needs of people living with chronic kidney disease."

The Corporate Innovator Award was established to recognize companies that advance the field of nephrology by addressing an unmet medical need, or improving upon an existing practice, therapeutic, or technology.

"Otsuka continues to make significant investments in our nephrology research and development and is committed to meeting the long-term unmet needs of people living with chronic kidney disease."

"

Louis Allesandrine, VP, Oncology and Renal Sales and Marketing, Otsuka Pharmaceutical, Ltd.

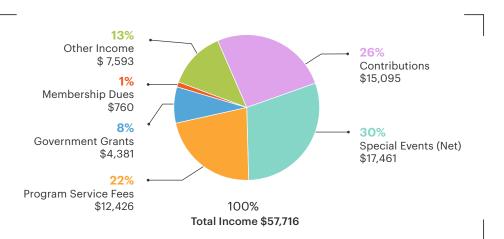


NKF CEO Kevin Longino, right, presents award to Otsuka's Louis Allesandrine.

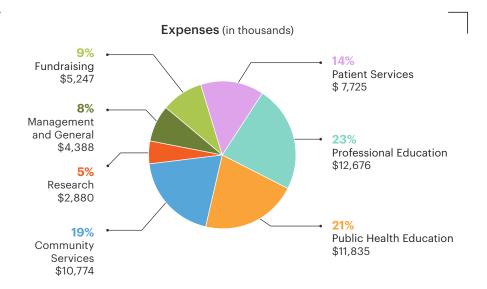
# **TOUR FINANCIAL OVERVIEW**

Thousands of people like you around the country have given their time, talent, and treasures all year to raise millions to fund important work led by NKF. People joined NKF Walks around the country, donated vehicles to Kidney Cars, attended galas, hit the links in tournaments, and gave generously through our Hero Circle or with one-time gifts to support NKF. We are thankful for the many thoughtful contributions.

Figures depict the combined financial activities of the National Kidney Foundation and its Affiliates for Fiscal Year 2019.



Public Support and Revenue (in thousands)



Total Program Expenses \$45,890 (83%) Total Support Expenses \$9,635 (17%)

100% Total Expenses \$55,525

Assets (in thousands)	
Cash and Cash Equivalents	\$10,540
Investments	\$26,062
Accounts Receivable	\$5,185
Inventories of Educational and Campaign Material	\$137
Prepaid Expenses	\$1,542
Property, Plant and Equipment (net)	\$5,239
Other Assets	\$4,142
Total Assets	\$52,847

Liabilities and Net	Assets (in thousands)
---------------------	-----------------------

Liabilities Loans Payable	\$501
Accounts Payable and Accrued Expenses	\$6,404
Deferred Income	\$6,521
Other Liabilities	\$477
Teach Link States	¢12.002
Total Liabilities	
Net Assets Without donor restrictions	
Net Assets	
<b>Net Assets</b> Without donor restrictions	\$25,690
<b>Net Assets</b> Without donor restrictions With donor restrictions	

### INDIVIDUAL SUPPORTERS

Jov Rohadfox\*

Aptekar

Cheafsky

Frechette

Gerzema

Gilbert

#### \$450.000+

Arthur and Gail Pasquarella\*

#### \$100.000+

Kevin Longino and Mary McDowell\*

#### \$50,000-\$99,999

Ron and Joy Paul

#### \$25,000-\$49,999

Richard and Rosann Noel Heather Pushinsky Paul and Joan Rubschlager Mark and Judy Schwartz The Snyder Family Sumeska Thavarajah'

#### \$10,000-\$24,999

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John Andrews

Paul Andrews

Maria Ansari

Salvador W.

Antonetti

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James Godwin

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Daniel and Daphna Raskas\* David Reader Patrick Reardon Dr. James Redington\* Frances Reed\* Michael Reefe Marie and Lamar Reese\* Bruce Reeves Sandy and Gene Reid Robert Relph Phil Renaud Amy Rennert Salah Reyad Jeanne Rezuke\* Matthew and Jessica Rhenish\* David Rice Jess Rice Susan Rice Danny A. Richards Virginia Richardson Renee Richardson Gosline\* Debbie Riddle Eleanor Ridley\* Mary Riggin\* Mark Rinker Arichay Rithiphong Angel Rivera\* Doug Roberts Jim Roberts Sammy Robillos lack Robins David Roemer Joseph Rogers\* Kenneth L. Rogers Frederick Rohn Jim Rolfe **Ricardo Rollins** Catherine Romano Antonio Romanucci Alain Romero Gabe Romero Dr. Dennis and Mrs. Ann Ross<sup>1</sup> Howard Ross' John Ross\* Chris Rossi Donna Roy Lon Rubackin Ramon Rubio

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**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.

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# **INKF SERVING THE LOCAL COMMUNITY**

Fueled by passion and urgency, dozens local offices and Affiliates of the National Kidney Foundation work hard around the nation to help all people affected by kidney disease. In the following pages, please read just some of **the highlights of their efforts in FY19**. In addition to the NKF's National Office, NKF's 29 local offices and 9 affiliate offices around the country are working hard to raise awareness and money, and serve professionals and patients with kidney disease. Each office has its own board, volunteers, and staff focused on their community's unique needs and NKF's mission. Here are just a few highlights from around the country:

NKF Serving Greater New York raised a record \$1.1 million dollars at the New York City Kidney Walk through the dedication of kidney patients, their families and the community. GNY touched the lives of more than 100 kidney patients by distributing care packages to dialysis centers and educating 125 patients about living donation during THE BIG ASK: THE BIG GIVE training. They worked for the passage of the Living Donor Protection

Act in New York State. Now living donors are protected from insurance discrimination.

The NKF Serving Eastern PA & NJ (Philadelphia) local office got Philadelphia's attention when the city's skyline shined orange to raise awareness for kidney health during National Kidney Month. Staff, local board members, and volunteers delivered 250 care packages to dialysis patients on Giving Tuesday for the Drive for Dialysis program. With 3,000 people involved, Philadelphia's FY19 Kidney Walks raised nearly \$700,000 and generated over 200,000 local media impressions for the Heart Your Kidneys campaign. The NKF Serving the National Capital Area local office focused heavily on patient education and empowerment, piloting THE BIG ASK: THE BIG GIVE in-person trainings and the "Kidney Disease: What You Need to Know" presentation. They also partnered with NKF's Government Relations team to hold the Kidney Patient Summit on Capitol Hill and NKF's Congressional Awards Reception, key events that engage and educate Congress about living donation and kidney disease.

The team of volunteers and staff at NKF Serving Texas secured a Blue Cross Blue Shield grant that nearly tripled KEEP® Healthy efforts in Texas and resulted in over 3,000 screenings in the program's first cycle. Recently renewed for another cycle, the grant enables a partnership with the Caring Foundation of Texas and the use of a Care Van for screenings.

The NKF Serving Columbus office hosted the first THE BIG ASK: THE BIG GIVE at Nationwide Children's Hospital in addition to another workshop with Lifeline of Ohio during their Patient Summit. NKFCO ended the year by successfully holding their annual Kidney and Transplant Symposium during National Kidney Month, featuring NKF President, Dr. Holly Kramer, as the Keynote speaker with special guest Dr. William Fissell from

NKF Serving Northern California's crew hosted their 30th Annual Authors Luncheon with nearly 1,000

Vanderbilt University Medical Center.

guests who raised \$500,000, and NKF Kid Ambassador Angelica Hale sent in a congratulations video to help celebrate the milestone. In addition, the Young Professional Board's 3rd Annual San Francisco Kidney Ball reached new heights, with 300 guests raising \$70,000. Local Kidney Walks also did well, with 2,700 walkers raising a record \$700,000 to support the kidney community.



NKF Serving South Carolina hosted over 300 dialysis patients at the *The Patient Empowerment Workshop* in Columbia, SC.





### NKF AFFILIATES

#### **NKF of Arizona**

NKF of Arizona screened more than 1,400 Arizonans through Path to Wellness, a community health program that tests for diabetes, heart and kidney disease. More than 1 in 5 participants were found to have evidence of kidney damage.

#### NKF of Florida

NKF of Florida completed its second year of financial distributions from the Hawthorne Patient Assistance Fund to cover the cost of immunosuppressant drugs for post-transplant patients. Over \$40,000 was distributed to 41 different transplant recipients last year.

#### **NKF of Louisiana**

This past year, NKFL participated in over 25 health fairs, conducted 14 kidney health-checks, 20 HCA education programs, as well as their first THE BIG ASK: THE BIG GIVE in-person training. NKFL also continues its work on engaging medical students about careers in nephrology and supporting interprofessional education on renal health. Through their statewide public health education campaigns, they reached over 100,000 residents and coordinated several living donor seminars.

#### NKF of Utah & Idaho

NKFUI provided continuing medical education to over 500 professionals in partnership with the Ogden Surgical Medical Society in order to advance earlier diagnosis, prevention, and treatment of kidney disease. Through its Kids and Kidneys program, NKFUI reached an incredible 10,685 junior high students through an interactive video program about kidney health and the importance of organ donation.

#### NKF of Hawaii

NKFH celebrated National Kidney Month with its 3rd annual Walk on the Wild Side fundraiser, a huge outdoor community event that spanned eight blocks. Over 3,000 families attended and received free kidney and vision health-checks, and enjoyed a day of food trucks, live music, and games while learning about kidney health.

#### **NKF of Indiana**

This year, NKF of Indiana continued its work of sending kids with kidney disease to overnight summer camp free of charge. Kids ages 8 to 18 who have CKD or received a kidney transplant enjoyed five days of summer fun at Camp Tecumseh in Brookston, Indiana in June.

#### NKF of Illinois

On World Kidney Day, more than 40 advocates assembled in the Illinois State Capitol to support legislation granting living donors tax credits and protection against discrimination.

#### **NKF of Michigan**

The NKF of Michigan proudly served more than 80,000 people this past year through direct programs and services, including the Diabetes Prevention Program and Regie's Rainbow Adventure<sup>®</sup>.

#### **NKF of Wisconsin**

Healthy Shelves, a statewide food pantry community outreach program of NKF of Wisconsin expanded its work of promoting healthy food donations to improve the nutritional health of food-insecure individuals living with diabetes, heart, or kidney disease.

NKF of Illinois Director of Programs Megan Craig and Evan Simms, 9, who received a kidney donation from Megan, testified before the Illinois Senate committee on World Kidney Day.

# **WHAT'S TO** COME IN FY20

In our quest to eliminate all preventable CKD, increase the number of kidney transplants, and ensure that all dialysis patients have the chance to lead full, productive and functional lives, we have some exciting initiatives coming soon. Here is a brief summary of what you can expect from NKF in FY20.

#### We are launching the NKF Patient

Network, an interactive registry of patients with kidney disease. As the online platform builds, patients will be able to get personalized information to help them navigate their disease; find clinical trials that help in the battle with the disease; or connect with specialists or facilities working in the forefront of kidney medicine. It is our hope that, eventually, scientists will have access to the largest data set of patients and their experiences, which will help them better understand overall kidney health and accelerate drug development. The possibilities are endless, and we hope this will become an incredible resource for as long as there is a need. The NKF Patient Network was announced in May 2019, and we expect active enrollment to begin in May 2020.

#### Also, we are funding a new prize

contest for kidney patients that could help "build a better mousetrap" when it comes to living full, productive and functional lives. The contest will award cash prizes to patients for their homegrown ideas and life-hacks that help them manage CKD or ESKD. KidneyX: Patient Innovator Challenge, funded by NKF is a public-private partnership between the U.S. Department of Health and Human Services and the American Society of Nephrology. We can't wait to see what these intrepid kidney warriors dream up.

You will also see some **changes coming to our website in FY20**. We are redesigning this important platform for patients seeking information about CKD. We think the new design will be simpler and easier to navigate than our old site. Please let us know what you think, too!

We are also rolling out a major **education series called "Kidney Pathways"** that we hope will enable patients in all stages of CKD to better understand the disease and play a more active role in managing their care. Kidney Pathways is an online system that delivers a curriculum-based format offering need-to-know essentials that align with CKD risk factors and laboratory findings reported in the online health assessment.

President Donald J. Trump signed an Executive Order with a bold vision for transforming kidney care for the 37 million of Americans affected by kidney disease. During a speech in July 2019, attended by NKF volunteers, patients, care partners, and leadership, as well as government officials and other kidney organizations, the President laid out a detailed plan to:

 Help increase living and deceased organ donation;

- Increase earlier detection and care
   of CKD; and
- Increase incentives to develop new, cutting-edge treatments, including advancing home dialysis.

We look forward to working with the Administration on this transformation.

We know that FY20 will bring so many advances in our fight against kidney disease and that is in large part because of our many stakeholders. Thank you!



NKF CEO Kevin Longino, top left, joined stakeholders on the stage in July when President Donald J. Trump signed the landmark Executive Order.



30 East 33rd Street New York, NY 10016 **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**.

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