



National
Kidney
Foundation®

Annual Report FY 2016

Present Actions, Immediate Goals, and The Vision

To Our Supporters and Potential Supporters,

Our work is about making futures possible for people with chronic kidney disease (CKD). Helping a life continue is like letting a story continue. From someone with CKD getting to raise their child, to a student graduating school, to a person making career goals, we see how people's stories turn out through early detection, improved treatment, and access to life-saving transplantation.

NKF has a story, too, a continuing story of hope, of action for change—and of people.

A mother sits at a kitchen table worried about her sick child. She refuses to accept fate. She rejects the status quo. Things must change. She takes action. Here our story begins.

Ada DeBold, our founder, created this organization to find better treatments for her son. From that beginning to today, where we are putting the full force of this organization behind raising kidney disease to a national priority, NKF is a people story: people making change happen, people living that change, and the people we continually seek to help. Hence, this year's theme: People First.

This account of the past year is one of progress for people with kidney disease, their families, and those at risk. Through several major initiatives, we are changing the reality of kidney disease, which means changing the reality of millions of daily lives.

Major highlights of this year include: the further rollout of our most ambitious initiative to date, CKD*intercept*®, which is making substantial headway in earliest detection of CKD in primary care patients and in prioritizing kidney disease nationally; introducing the Living Donor Protection Act in Congress to help kidney donors across the country; a 19 percent increase in people accessing the NKF Cares Patient Information Help Line; and the launch of the Professional Education Resource Center (PERC), including 25 new courses for kidney healthcare teams to improve treatment.

This is only some of the work we've accomplished this year. Turn the page; our story continues for the people we serve—

Art Pasquarella, CRE
Chairman

Jeffrey S. Berns, MD
President

Kevin Longino
Chief Executive Officer



ART PASQUARELLA, CRE

Chairman



JEFFREY S. BERNs, MD

President



KEVIN LONGINO

Chief Executive Officer

Leading the Way Against Kidney Disease:

CKD*intercept* is NKF's next big step against kidney disease. NKF was the first to define chronic kidney disease to facilitate diagnosis. We also separated the condition into stages for treatment, now a worldwide standard, and we release and continue to update guidelines that are improving treatment for millions. Now, CKD*intercept* is raising kidney health and prevention of kidney disease to a national priority and taking steps to change the way the primary care system works with regard to CKD. Component programs will address every aspect of earlier intervention: professional education for primary care physicians and the kidney healthcare team; patient data analysis to find people with beginning or active kidney disease; coordinating practices and information sharing between stakeholder organizations; changing the way lab results are reported to doctors and patients; public and patient awareness activities; government advocacy; and other programs.

PEOPLE FIRST

The National Kidney Foundation is not about kidney disease. It's about people with kidney disease. That's an important distinction to make. Kidney disease is life threatening and our first job is to find ways to save and improve as many of these lives as possible, be it through early detection, increasing organ donation, or public awareness efforts that encourage people to get tested for early kidney disease. It's about countering this condition and unlocking the potential for better futures in people's lives.

Ada DeBold, our founder, started this organization in 1950 to find a cure for her son. Unfortunately, that didn't happen, but Mrs. DeBold went beyond her own situation and saw the value of what she and her family were doing for millions of other people. Today, we follow through on that commitment. Here is NKF at work:

Making futures possible....

At one time, a diagnosis of kidney disease meant that a person's life was over, their future "cancelled." The Foundation took the lead among healthcare organizations to ensure that is no longer true. Today, people with kidney disease live much longer, but more work needs to be done.

To make more of those futures possible, to extend and improve the lives of the many people with kidney disease, broad

action is needed in the healthcare system, public awareness and education, government advocacy, and in communities across the country.

The first step in dealing with a problem is to learn that it's there. Awareness is key to our mission. Chronic kidney disease is about time—the earlier it's caught, the better. Imagine catching kidney disease in millions of people *even before* it starts to do significant damage.

This is a goal within our reach. But to do this on an effective scale, people all over the country need to begin to recognize the real importance of chronic kidney disease (CKD) in their daily lives, classifying it for what it is—a major public health issue requiring action. In 2014, we launched our most ambitious initiative to date, **CKD*intercept***, which will change those perceptions and actions.



This year, we invited major healthcare stakeholders to a **CKDintercept Summit**, which included top-tier representatives from healthcare systems, clinical labs, and other areas. The goal of the summit, a sub-program of *CKDintercept*, is to bring leaders together to identify obstacles that impede early detection in primary care and recommend strategies to overcome them. An event of this importance—a virtual “change everything” summit—requires a great leader. **Regina Benjamin, MD, MBA, the 18th Surgeon General of the United States** has agreed to Chair the *CKDintercept* Summit. Dr. Benjamin brings her experience with large scale public health initiatives, as well as her understanding of the business community as the owner of a clinic, in providing substantive, practical leadership to the summit, while championing the idea that something on this scale can be done. Her participation was of significant interest to the public; the release sent out on World Kidney Day announcing Dr. Benjamin’s acceptance of the chair position was picked up by 205 media outlets.

CKDinform, the professional education component of *CKDintercept*, is changing the way kidney healthcare professionals think about and act on CKD. Live and online continuing medical education courses focus on earliest detection and treatment in primary care offices. NKF’s Kidney Learning Solutions (KLS), our professional and patient education department, began to roll out this **three-module program** through NKF’s local offices around the country. We have reached more than 3,000 learners, and the numbers continue to grow.

The *CKDintercept* strategy to **analyze patient data and find undiagnosed kidney disease has produced the most striking results so far. This “data mining” program has already found 200,000 people with probable undiagnosed CKD** and is taking steps to engage them and

their primary care clinicians in programs to improve CKD assessment, diagnosis and treatment.

Through these and upcoming efforts, *CKDintercept* continues to alter the landscape of CKD detection and treatment. This initiative also keys in on a major, life-saving mandate of NKF: **public awareness for early detection...**



REGINA BENJAMIN

U.S. Surgeon General (2009 – 2013)



In today's intense media environment, unconventional, attention-getting approaches are needed to cut through the media "noise." Last June, NKF launched the humorous educational video and website **Everybody Pees**. The irreverent, animated video caught the eye of **1 million viewers on YouTube** and the accompanying website proved to be enormously popular. The messaging involved, of course, urine testing for kidney disease, as well as the overall importance of kidney health. Posters, ads, and other publicity materials were also distributed. This limited campaign succeeded in cutting through the media "noise"; the slogan was even cited in the lead of a December *New York Times* story—about politics! Through the use of humor, the Everybody Pees campaign helped connect our message to current culture.



Getting in Front of the Problem: Public Awareness

What's the first step in saving lives?

Very simple: Warn people.

Not so simple: Getting the message out to people where they see it, and just as importantly, getting them to listen and act on it.

A major part of NKF's work is "getting the word out" through awareness efforts. The public needs to be educated about the urgency of kidney health. One in three people are at risk for kidney disease and this increased risk cuts across several major demographics (e.g., African-Americans, Hispanics, Asians, the elderly). Early detection is crucial to slowing or stopping kidney disease and can be achieved through two simple,

inexpensive tests (blood and urine). Were more people to do this, untold amounts of suffering and billions in healthcare expenditures could be saved. Therefore, NKF seeks every opportunity possible to find and tell people at risk to get tested.

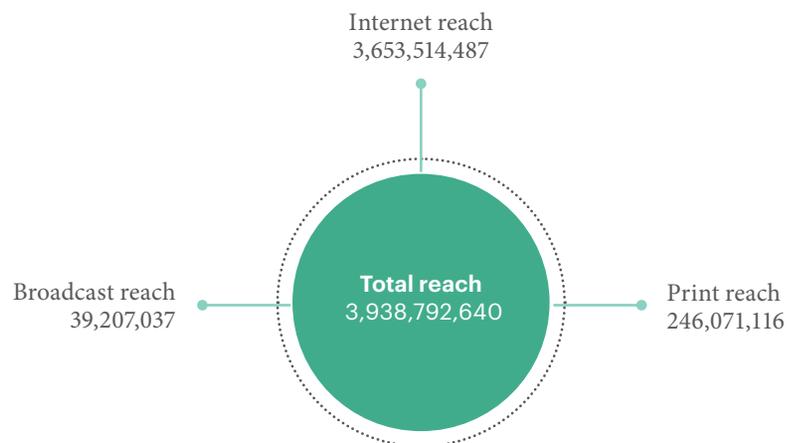
Public awareness is a mission mainstay. Like the rest of the world, our increasing emphasis is on connecting to people through **social media**. NKF uses its social media presence as a vehicle to educate people, from prevention tips and kidney-healthy recipes to inspiring stories from living donors. With more than 175,000 social media fans and growing, NKF rallies our communities around common values and life stories.

NKF is a growing, dynamic presence on **Facebook®, Instagram, and Twitter** for people affected by CKD, including

transplant recipients and donors, government advocates, and the general public. Social media is a real growth area for the Foundation because of its unlimited potential to connect with—and help—large numbers of people. Stay tuned and keep an eye on your smartphone for the latest developments!

It's important to remember that every media "impression" of our awareness message represents a possibility for saving someone's health. Therefore, NKF continues its robust presence in "traditional" media, ensuring that our message is everywhere possible.

NKF Media Reach

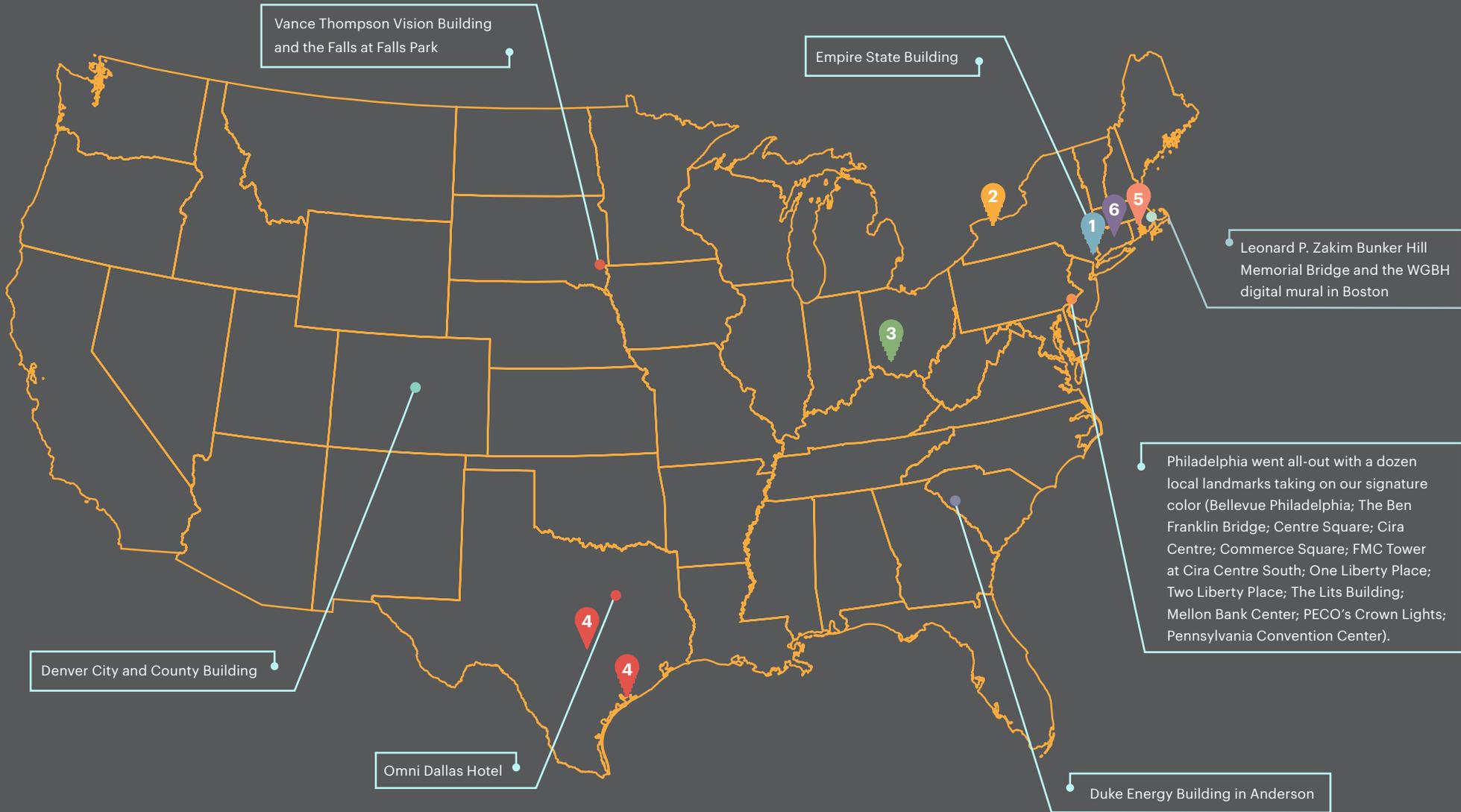




National Kidney Month Across America:

Local NKF offices were at work everywhere to make National Kidney Month a truly national event.

In fact, the entire country “turned orange” that day, with many local landmarks displaying our color.



National Kidney Month and **World Kidney Day in March** are our peak times to **get out the message** of kidney health. This year was particularly successful. NKF offices across the United States were united against kidney disease.

1 The **Empire State Building** glowed orange, NKF's official color, on World Kidney Day to remind the public of kidney disease in our midst. Downtown in New York the next day, NKF CEO Kevin Longino and Chairman Art Pasquarella, along with staff from **NKF of Greater New York**, rang the **closing bell at NASDAQ**, which also featured the NKF logo and messaging on its website and its **Times Square jumbotron**. The *New York Times* featured a front page story, including a quote from NKF President Jeffrey Berns, MD, on a **groundbreaking new procedure** for kidney transplants. Exciting research points to a future where almost *anyone can donate a kidney to anyone*, instead of the laborious tissue-matching procedures going on now.



2 During National Kidney Month, **NKF Serving Upstate New York** successfully held a premiere “Patient Nutrition Education Program,” with 60 attendees.

3 **NKF Serving Greater Cincinnati** held a WKD breakfast at Cincinnati Children’s Hospital Medical Center with 150 people in attendance, including the Mayor of Cincinnati, John Cranley; Mike Stevenson of the NKF National Board of Directors; and other dignitaries.

NKF activities during National Kidney Month were covered by television stations in New York, Denver, Washington D.C., and Connecticut. In addition, more than 100 **patient advocates** met with more than 170 **government officials** that month regarding improvements in research and healthcare coverage. Altogether, 2016’s National Kidney Month and World Kidney Day were a winning season for NKF and in the lives of many people affected by kidney disease. We look forward to extending our reach even further in the year ahead.

4 **NKF Serving Texas** hosted a KEEP Healthy event for 150 people, which was covered by the local Fox News and Channel 11. There was a press conference at Texas Children’s Hospital nephrology unit, where Billy the Kidney passed out gifts to kids. The Texas Division also hosted a Patient and Community Luncheon for National Kidney Month. In Austin, both the governor of Texas and the mayor signed proclamations.

5 **NKF Serving New England** held a KEEP Healthy screening at Boston City Hall. Boston also hosted an NKF Celebrates! fundraiser and educational event at the Museum of Science. The New England Revolution Home Opener soccer event featured Sidney the Kidney taking the field with a living donor.

6 **NKF Serving Connecticut and Western Massachusetts** held a Kick-Off Party with the Bridgeport Sound Tigers where Sidney the Kidney was on the ice for the opening face-off.

Social media powered our efforts during National Kidney Month.

 **Facebook** posts that month earned 2.9 million impressions.

 **NKF online** videos: 66,000 views.

 **Tweets** were seen by 185,000 people with almost 650 re-tweets.

 **Instagram** got 1,500 likes.

 **YouTube** videos earned an additional 1,000 views.

Awareness and public education are only parts of the job of reducing and stopping kidney disease. Awareness needs to be coupled with action. Hitting kidney disease “where it lives”—in particularly **at-risk communities** throughout the country—is another way of getting at this problem.

The hands-on work of making futures possible, of really improving and extending lives, means getting out there among people, into **communities at increased risk** for kidney disease. NKF connects directly with these people through **neighborhood kidney health checks**.

KEEP Healthy events truly embody our mission by **connecting with at-risk people on a one-to-one basis**. They are the most visible way to see the immediate benefit of NKF’s work.

In low-income areas that have limited interaction with the healthcare system, these events can be particularly effective in saving people’s health. More than 9,200 people participated in more than 100 KEEP Healthy events around the country in FY16.

NKF **improves people’s lives across the spectrum of kidney disease**, from the earliest stages to kidney failure. **Dialysis and transplantation** are the only treatments for kidney failure. NKF advanced **kidney transplantation** before it was commonly known as a treatment.

No one likes waiting, but imagine doing so with your life and health at stake. More than 100,000 people are on the kidney **transplant waiting list** in the United States. Approximately 18,000 people received a kidney transplant last year. And every year the list grows longer. This waiting has to end.

The astonishing fact is that a lot of this waiting can be eliminated. One of our signature efforts is to increase both living and deceased donations.

Lifesaving transplantation is a two-sided equation. **“The Big Ask/The Big Give,”** a multimedia public awareness campaign, provides education and support to potential living donors and to those waiting for a kidney. To a person needing a kidney transplant, asking someone to consider kidney donation can be difficult. Some people are so reluctant to ask, they put their health at risk. A person thinking about donation can feel intimidated by the idea and needs to know that people can live normally after the procedure. This educational campaign raises awareness about living kidney donation, educating not only kidney patients having difficulty asking someone to consider donation (The Big Ask) but also potential donors (The Big Give). This program provides factual, unbiased information addressing common concerns and offers support in making decisions about living kidney donation. “The Big Ask/The Big Give”

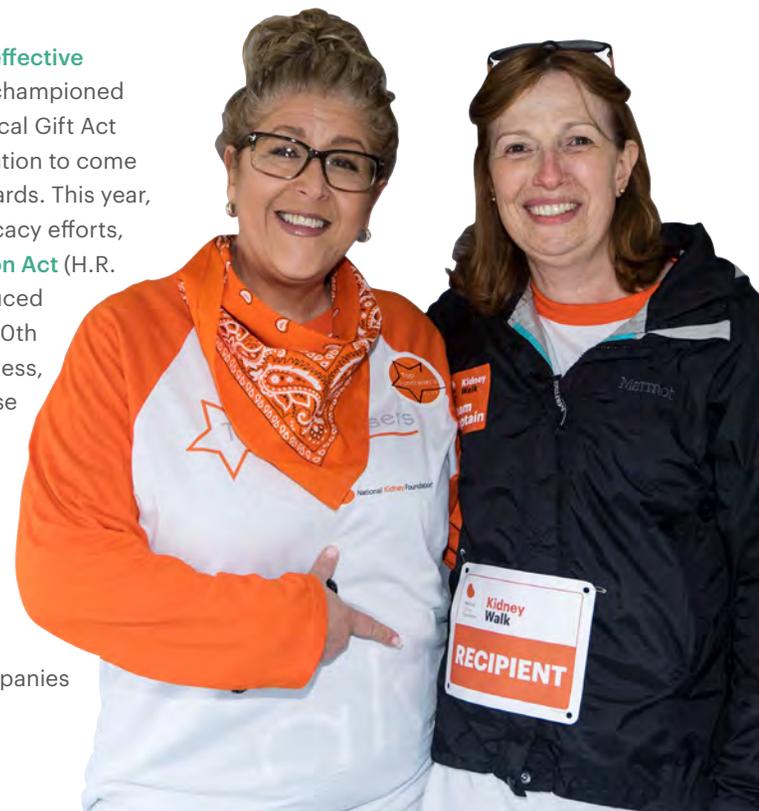
has been successfully pilot-tested in the Atlanta area and will be rolled out nationwide to transplant centers, dialysis centers, and nephrology practices in fall 2016. The goal is nothing less than freeing up a huge potential for saving lives.

It is difficult to describe the incredible generosity involved in donating a kidney to someone—a family member, a friend, or even a stranger—so that they can live. Even more difficult to understand is that these wonderful donors are often financially penalized for their selfless acts. You might say to yourself, “There should be a law against that!” NKF feels the same way and is doing something about it in Congress.

NKF has a long history of **effective legislative advocacy**. We championed the 1968 Uniform Anatomical Gift Act and were the first organization to come out with organ donation cards. This year, with the help of NKF advocacy efforts, the **Living Donor Protection Act** (H.R. 4616/S. 2584), was introduced by Rep. Jerrold Nadler (D-10th NY) and Rep. Michael Burgess, MD (R-26th TX) in the House of Representatives, and Sen. Mark Kirk (R-IL) and Sen. Kirsten Gillibrand (D-NY) in the Senate. This bill will protect living organ donors and remove barriers to donation by prohibiting insurance companies

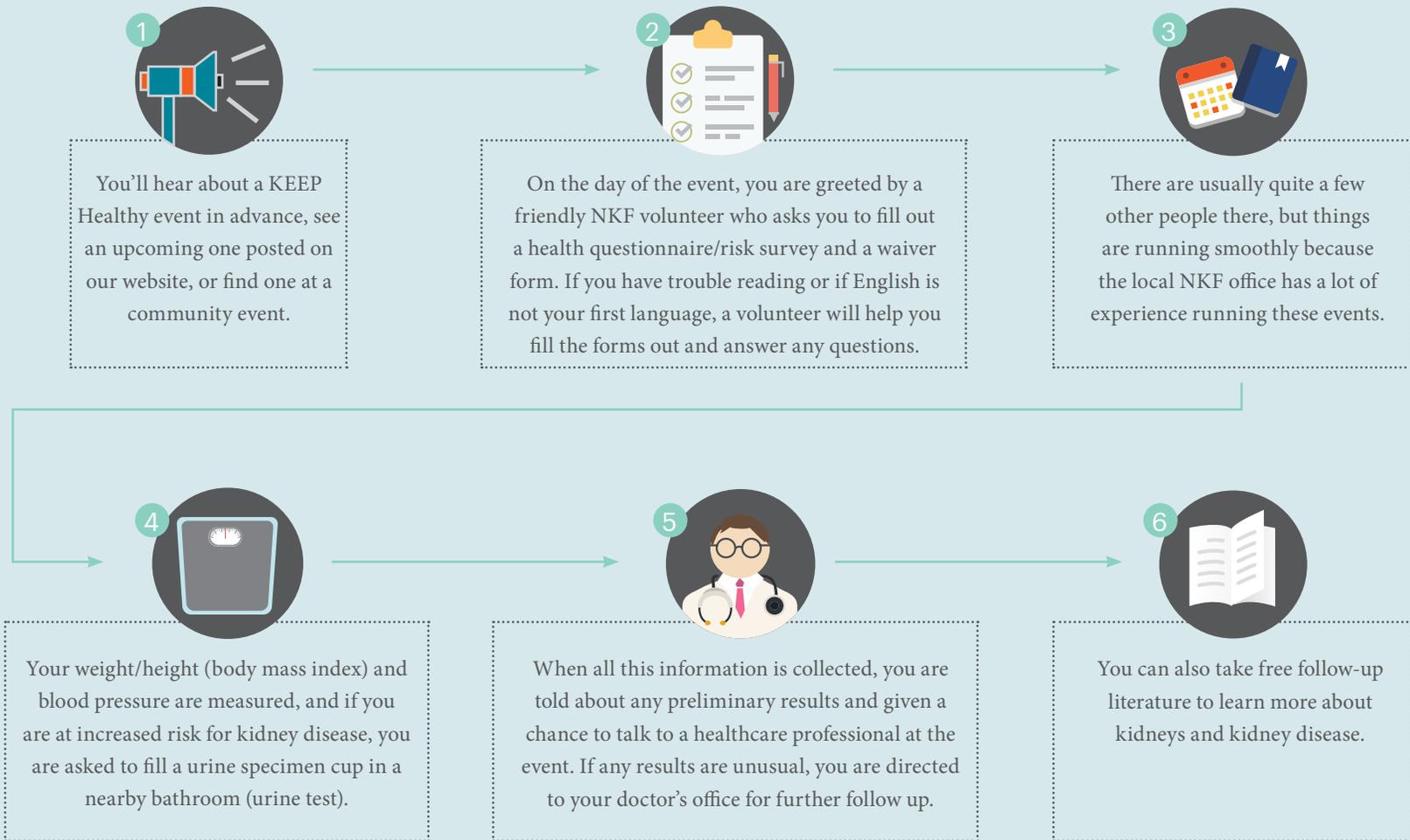
from denying or limiting life, disability, and long-term care insurance to living donors and from charging higher premiums. The bill also clarifies that living organ donors may use time granted through the Family and Medical Leave Act (FMLA) to recover from donation. This legislation represents a major step toward supporting living donation and getting kidney patients off the waiting list. (More on Government Advocacy on page 42.)

Making futures possible is more than just extending lives. The *quality* of that added time is equally as important...



KEEP Healthy events educate people about kidneys, risk factors for kidney disease, and steps to take to keep kidneys healthy and reduce risk.

A typical **KEEP Healthy** event might go like this:



The Homework Assignment that Changed Two Lives:

Teacher and Student Become Donor and Recipient



Jennifer Adams

Moriarty, NM

The assignment was to pick something personal and life changing, write an essay about that event, and present it to the class. Little did the instructor, Jennifer Adams, realize that an assignment to describe a life changing experience would itself transform her life forever.

While working at the School of Adult and Basic Education at Central New Mexico Community College during the fall 2013 semester, Jennifer learned how kidney disease really changes a person's life.

She told students that they would share their personal essays with the class, and that it would be their opportunity to teach their classmates about what they believed to be most the important thing in their lives. On the day of presentations, the students had many different stories they shared, each one personal and meaningful, but one in particular really stood out to Jennifer.

A single mother of a six-year-old girl read her essay about the day she should have died. The silent, attempted killer was kidney disease. Melinda, the student, told about how she had become so ill she couldn't get out of bed. She felt sick for about a week beforehand and couldn't take it anymore. Melinda asked a family member to take her to the emergency room where she found out that both of her kidneys had completely failed, and her body had been filling up with toxins. She immediately started dialysis.

At the time she shared her essay assignment, Melinda had been on dialysis for four years and had both of her legs in boots because of broken ankles that wouldn't heal. She told her story so the class could learn about kidney disease and be aware of it themselves. She had no clue herself about the disease before both of her kidneys shut down. She went on to describe how kidney disease had

changed her life completely—her dialysis treatments, the impact on her daily schedule and ability to work, and the effect it had on her daughter.

As Jennifer listened, she found herself terribly moved and impressed by Melinda's story, so moved that she wanted to help her. She had never known about kidney disease before that day.

That weekend Jennifer talked to her husband and her family about becoming a possible kidney donor for Melinda, and they agreed to be supportive. The next week she told Melinda that she wanted to be tested to see if she was a match for a transplant, and two months later Jennifer learned she was a match. On July 9, 2014, a life was shared. Melinda received one of Jennifer's kidneys and the procedure was a success. Melinda began on the road back from all that kidney disease had taken from her life. These days she's getting an A+ in health.

The miracle worker, Jennifer Adams, lives with her family in Moriarty, NM. She and her husband, Chris, have a four-year-old son, Kyle, and a five-year-old daughter, Tuesday. In addition to being a full-time instructor at Central New Mexico Community College, she is currently working toward her PhD in Teaching, Learning, and Teacher Education.

This teacher could teach all of us about giving. As an advocate for her friend and former student Melinda, Jennifer volunteers locally as the New Mexico Kidney Advocacy Committee (KAC) liaison for NKF. Within this position she has presented Your Kidneys and You at local health fairs, was the chair of the 2015 Kidney Walk and upcoming 2016 Walk in Albuquerque, NM, and continues to work to spread awareness and promote prevention of kidney disease.

... moved and impressed by Melinda's story, so moved that she wanted to help her...

NKF Cares

NKF Cares is our Patient Information

Help Line (855.NKF.CARES

[855.653.2273]; nkfcares@kidney.org),

where anyone affected by kidney

disease—a patient, a family member, a

potential kidney donor, or someone at

risk—can talk to a trained information specialist who will listen, provide support and resources, and send free educational information. NKF Cares served more

than 14,000 people across the country

in FY16—a 19 percent increase from the

previous year. In FY16, NKF Cares sent

out 73,525 brochures to help educate and

empower patients and their families.



Making lives happier....

Don't settle for less. That's our message to people with kidney disease. One of our major aims is to help people not to identify as "a patient" or just "someone with a chronic illness."

Living with kidney disease is complicated. Whether it's deciding what to eat when you're on a kidney diet, what to do about work when you need to schedule dialysis treatments, or even how to bathe when you have a dialysis portal that needs to be protected, tasks that were once done without thinking now have to be carefully planned. Some can become "mini-crises," and dealing with them over a long period can be very wearing on patients and families. We are a go-to resource for people dealing with this chronic condition so that life is easier and more enjoyable.

When you need help, the first thing you usually think of is reaching out to another person. Online and print information are helpful, but there is nothing like talking to (or writing, or emailing) someone who's been in a similar situation. In today's strained healthcare environment, doctors, the healthcare team, and social workers have heavy patient loads and often cannot spend a long time with each patient. Questions can go unanswered. Concerns may have to wait until the next appointment, anxiety builds. NKF answers this need with some of our most effective patient programs, such as NKF Cares and NKF Peers.

Making each life better in the face of this disease is a priority for us. But to really change the lives of people with CKD, we have to change the way people think and act...



NKF's *Kidney Living* magazine went out to more than 50,000 people quarterly, delivering the latest news in better living for dialysis patients.



NKF Peers

Shared experience is a powerful connection between people. No one understands like someone who's "been there." With this in mind, NKF created **NKF Peers** (855.NKF.PEER [855.653.7337]; nkfpeers@kidney.org). Kidney patients are matched up with other patients who have been through a similar situation. Each year about 100 people seeking support are matched with a peer mentor. NKF recently expanded this program to connect living kidney donors with people considering donating a kidney.



From Making Beats to Beating Kidney Disease:

Chris Melz-From DJ to RN

If you ever get into serious trouble, you'll want to have a friend like Chris Melz.

Chris' junior high friend, Will, was in big trouble. He'd been in and out of the hospital with diabetes, and then his kidneys began to fail. On the day Will started dialysis, Chris called the hospital and began making inquiries about becoming a living donor. Chris didn't know much about living donation, but he did know he needed to help his friend.

The Huntington, Long Island-based DJ went through the extensive testing procedure to become a living kidney donor and found that he was a transplant tissue match with his friend. After determining that he could live a healthy life on one kidney, the doctors gave Chris the green light.

Living donation of a kidney, particularly to someone who is not an immediate family member, is an act of such astonishing generosity that it can be hard for most people to understand. Yet to listen to many of these donors, it sounds as if they are being given a gift themselves.

The transplant surgery was performed on April 21, 2009, eight months after that first phone call. The transplant went smoothly. Both Will and Chris came out of it in good health.

For Will, it was a new lease on life. For Chris, it was the start of a new way of thinking.

"What surprised me most, was not how I felt physically after the surgery, but how I felt mentally," says Chris. "I had been a radio personality and hip-hop DJ for 15 years prior to the surgery. I enjoyed every minute of being a DJ. I continued to do

"Being able to give a part of myself to someone else was an incredible feeling, and I wanted to do more."

it even after the surgery. However, the experience of the surgery opened my eyes to how short and long life is at the same time. Being able to give a part of myself to someone else was an incredible feeling, and I wanted to do more. While I was in the hospital I was able to see the important roles that nurses play in the lives of their patients. So in the fall of 2012, I made the decision to change career paths and enroll in nursing school. I knew that this would give me the opportunity to connect with people who are suffering from renal disease and allow me to share my story with others. I enrolled in Suffolk County Community College to take the necessary prerequisite courses needed in order to qualify for their nursing program. After a year and a half of prerequisites, I began their two-year nursing program. I will graduate the program this year.”

For the past five years, Chris has been speaking at various NKF workshops, sharing his story as a donor and kidney advocate. He also raises funds to support NKF programs and services and is an active Kidney Advocacy Committee (KAC) liaison. “The funds raised...help patients like Will, and donors like myself, live healthier, longer lives. I encourage those who are considering living donation to consider their work life and personal life as there are many things that may need to be put on hold. All that aside, in the end it is a wonderful feeling to be able to help another human being in this way.”

In addition to his careers as a DJ and soon-to-be nurse, Chris runs his own print shop, specializing in T-shirt screen printing, embroidery, and other basic print needs. We think he should print a T-shirt for himself that says “Hero.”



Chris Melz
Long Island, NY

Changing the patient experience....

How do people deal with having kidney disease? Studies overwhelmingly confirm that patients who are active, informed participants in their healthcare have better health outcomes, quality of life—and longevity. Therefore, NKF sets out to rally patients to be more proactive and to **educate** them in any way possible. Through this, *we change how patients react to their condition.*

Finding reliable, accessible, and practical information can be a challenge. A general web search can overwhelm a person and still not provide the answers being sought. Information can be conflicting, leading a patient to ask, “Whom do I believe?”

We’ve long prided ourselves on being the go-to resource for reliable and useful patient information, from diet menus to travel tips, to medical information that they can readily understand.

NKF’s Kidney Learning Solutions (KLS) Department provides content (brochures, the web-based A–Z Guide, fact sheets, mobile apps) with the input of kidney patients, families, and all members of the healthcare team working in frontline patient care organizations. Brochures are written in clear, easily understandable language, at a reading level designed to make the information accessible to as many people as possible. Many are available in Spanish, and we are **expanding our dual-language options**. We have just increased our library of Spanish-language patient brochures by 40 percent. We’re now up to 19 titles available for the rapidly increasing Spanish-speaking population. (For KLS Professional Education programs, see page 20.)

The patients themselves participate in creating effective educational materials. KLS has now incorporated the voice of the patient into *all* educational

materials. We collaborate with the new **Kidney Advocacy Committee (KAC;** see page 43.) to listen to the patients’ needs, allow them to tell their stories, and then integrate their experience into the content. Furthering this collaboration with the people we serve, we recently launched a live Facebook stream, moderated by a physician and a patient together. This platform engaged more than 5,000 patients and caregivers and resulted in so many questions that we had to respond to the overflow of queries through our NKF Cares Patient Information Help Line to ensure everyone got answered.

Social media and the web are ideal for carrying out our educational mission because they allow us to be there instantaneously when people need information. Patients find each other—and support—through our national and local Facebook pages and receive important updates on tips for living with CKD, events, and government issues.

Our website is consistently ranked first in search engines when people entered the terms “kidney disease” or “kidneys.” New media have even made eating easier through KLS’s My Food Coach app for kidney-healthy recipes and menu options.

Despite the growing predominance of social media, there is nothing quite like one person speaking directly to another. **“Your Kidneys and You” (YK&Y),** are volunteer-led **live educational presentations** on what kidneys do, risk factors, and steps for keeping kidneys healthy. They are held at community centers, workplaces, and other venues. Nearly 10,000 people attended live YK&Y presentations in their local communities and over 71,000 viewed the animated YK&Y video online.

Education is more than just passing on information. It’s opening up possibilities where they didn’t exist before, and through that, opening up lives.

Help should not have a language barrier.

El idioma no debe ser una barrera para pedir ayuda.



MY FOOD COACH APP
for kidney-healthy recipes

The Taste of Good Health:

The Kidney-Healthy Chef

For kidney patients, the expression “you are what you eat” is a very serious matter. Kidney disease throws off the entire body chemistry. Therefore, balanced nutrition is particularly crucial to good health and longevity for kidney patients, so much so that renal nutritionists practice their specialty at dialysis clinics everywhere.

Duane Sunwold is living proof that adhering to a kidney-healthy diet can change your life. This master chef was so successful with his own diet that he passes on his knowledge to help thousands of people. Mr. Sunwold may be the only person in the country who is a full-time Kidney-Healthy Master Chef.

Duane is an instructor at the Inland Northwest Culinary Academy at Spokane Community College. He has been nominated twice for the Who’s Who of Community College Teachers by his students. Duane has cooked from Idaho to Hawaii and been a guest chef preparing meals for athletes at the Calgary Winter Olympics in 1988.

Duane was diagnosed with chronic kidney disease in 2000. After 18 months of treatment, he changed his diet and started seeing significant improvements in his health. Today, Duane has been able to put his kidney disease into remission with his dietary changes and the guidance of his medical team.

When choosing the right foods can have a huge impact on your health....

Being restricted to a kidney diet used to mean “bland.” Enjoying eating is such an important part of people’s lives and, not incidentally, important to their psychological health as well. Duane also travels the country, educating dietitians on how to put flavor into patients’ diets. Kidney patients’ diets can be one of the most challenging to follow, because they change with the five stages of kidney disease. Many patients have to monitor the amount of potassium, phosphorus, and sodium in their food. It is also common for kidney patients to have other complications that require them to monitor their intake of liquids, protein, fat and carbohydrates. Duane’s customized cooking meets these needs.

Because of the great personal results from being an active participant in his healthcare, Duane volunteers for NKF. His work includes being a past Chairman of the Patient and Family Council and speaking before members of Congress in the Capitol Building about kidney disease and healthcare reform. He also does peer-to-peer mentoring with other kidney patients and develops recipes for NKF’s My Food Coach app. In 2015, Duane joined NKF’s Kidney Advocacy Committee (KAC).

No secret recipes from Chef Duane, just wishes for good health for everyone!



Duane Sunwold
Spokane, WA

NKF-KLS Professional and Patient Educational Materials

- Patient Brochures available as hard copies or downloadable PDFs
- Online Fact Sheets and Web-Based Content from the A–Z Guide
- Patient and Professional Videos
- Mobile Applications for Patients and Professionals
- Clinician Tools available for download or as hard copies (i.e., foldout pocket tools, clinical bulletins, clinician teaching cards, fact sheet tearoff pads)
- Accredited Professional Advancement CME/CE Programs (live and online)
- New KLS formats such as Facebook livestream patient/physician programs and the new NKF “Kidney Talks” video series

KLS Educational Programs grew from 42 in 2014 to 72 deliverables in FY16. These programs included online CME (continued medical education) programs, such as state-of-the-art clinical bulletins, patient brochures, videos, patient brochures, and new and timely website content.

Feeling better...

Having a good day is a gift, whether you have kidney disease or not. The more good days you have, the more they will eventually add up to a good life.

Having an “off day” or “feeling under the weather” means that you’re having a day when you’re not living life to its fullest. *Reducing the number of these days in the lives of people with kidney disease is one of our major goals.* A good day for someone with kidney disease also means a good day for

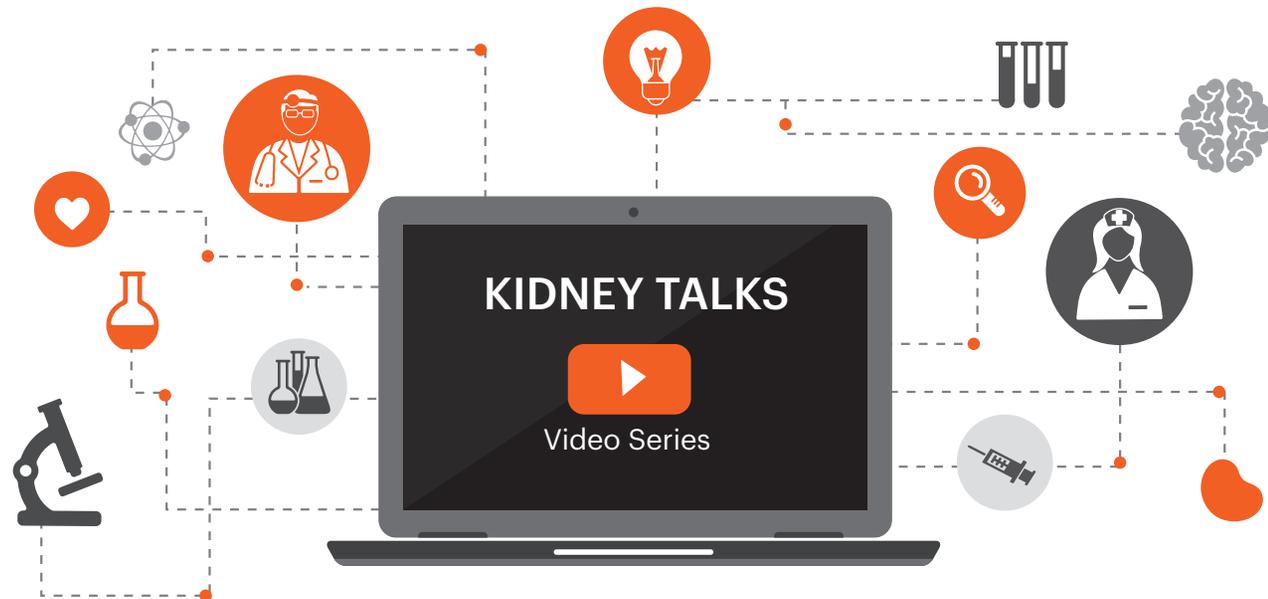
caregivers and an opportunity for family and friends to live more fully with the affected person—to enjoy who they are and the value they bring to the lives around them.

Improved treatment, beyond saving lives, means reducing debility from kidney disease and improving overall quality of life. Kidney disease is a complex condition involving virtually every system of the body and treating it is a real challenge for healthcare professionals. It requires **continual**

and diversified efforts to engage this problem and find new and better ways to treat it.

Keeping healthcare professionals up to date with the latest developments in kidney care is the job of **NKF’s Kidney Learning Solutions (KLS) Department.**

In addition to producing NKF patient education materials (see page 16), KLS has been **educating professionals** for almost 20 years. This team of award-winning kidney healthcare



Each year, NKF's Scientific Activities Department convenes a national educational summit for working kidney healthcare professionals, the NKF Spring Clinical Meetings (SCM).

For 25 years, nephrology healthcare professionals from across the country have come to SCM to learn about the newest developments related to all aspects of nephrology practice, network with colleagues, and present their research findings. SCM is designed to promote meaningful change in the multidisciplinary healthcare teams' skills, performance, and patient health outcomes. It is the only conference of its kind that focuses on translating science into practice for the entire healthcare team. In addition, SCM hosts the latest research findings through abstract poster presentations, showcases the latest products and services in the exhibit hall, and presents awards to exceptional practitioners in all disciplines for their contributions to patients and the field.

Sometimes even the professionals need help—particularly at the beginning of their careers. Last August, NKF inaugurated the **Pro-to-Go** program, which provides scholarships to promising clinicians and professionals who would otherwise not be able to attend SCM or access the training and

development it offers. "Getting new doctors into the field of nephrology is so important. The NKF Spring Clinical Meetings are great—it's exactly the type of event that will get a resident interested in nephrology," says Dr. Paul Olson, Pro-to-Go sponsor and member of the local NKF of Minneapolis board.

With the number of medical students entering nephrology decreasing and the demand for care increasing, the need for well-trained clinicians is an urgent issue in patient care. Pro-to-Go allows undeclared medical residents an opportunity to interact with, and learn from, leaders in every aspect of healthcare. For dialysis technicians, the Pro-to-Go scholarships help bridge the gap between their need for continuing education and the lack of reimbursement and paid time off they receive from employers nationwide.

Improved treatment through professional education means hope in patients' lives, from a better experience with dialysis treatment, to being able to go back to work, to simply feeling better...





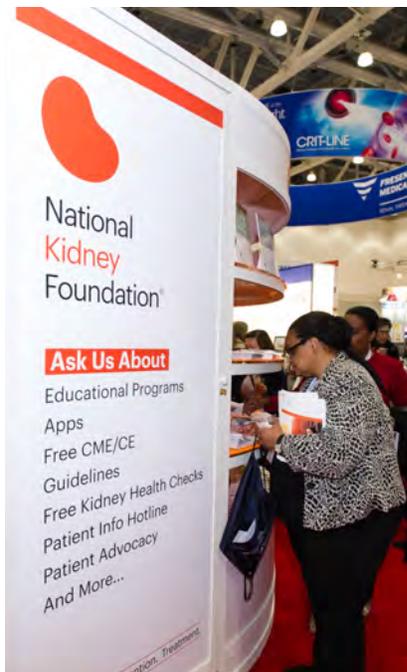
Scientific Conferences:

Professionals Team with Patients for Answers and Future Directions

“What we know,” “what we can do with what we know,” and “what we need to know.”

This year’s NKF Scientific Workshops were on “Introduction of Biosimilars into Nephrology Practice” and “Potassium Homeostasis in Disease and Health,” **two hot topics in kidney healthcare**. These workshops brought together a group of physicians, nurses, dietitians, pharmacists—and patients—to discuss “what we know,” “what we can do with what we know,” and “what we need to know” on each topic. The interactions between healthcare professionals and patients provided valuable insights into maximizing our knowledge for improved patient outcomes and prioritizing future research goals. A summary of the workshop deliberations is being published in the *American Journal of Kidney Diseases* to promote a better understanding of the topics in the nephrology community and the general population.

The workshops provided significant benefits to kidney patients. For example, the workshop on biosimilar drugs recommended a suggested naming system, so that these new and complex drug products could be more easily tracked in case there were safety issues, and formulated a consensus position statement that patients should not be switched to a biosimilar without being informed. The experts attending the potassium workshop proposed standardized definitions for evaluating the severity of abnormal potassium levels (a key issue in treating kidney disease) that will make it easier to do research and compare results across clinical studies. The workshops also inform NKF on critical information to include in our patient education programming.





The Ultimate "To-Do List"

Melissa Bensouda
Lee's Summit, MO

Think you're busy? Check out Melissa's "to-do list": care for three children, work a full-time job, undergo dialysis to stay alive, and fight kidney disease nationally. Recently, thanks to a lifesaving "gift from a friend," Melissa got to change one item on that list.

At 24 years old, Melissa Bensouda was diagnosed with CKD after giving birth to her second daughter. After her third child, she had lost all functionality of her kidneys. Her son was born 15 weeks early, and Melissa was on her way to visit her new baby in the neonatal ICU when she passed out in the hospital elevator. Her kidneys had failed as a result of IGA nephropathy (a disease that damages the tiny filtering units in the kidneys). Both kidneys failed,

forcing her to go on dialysis three days a week, and she was placed on the kidney transplant waiting list.

Melissa's story is an exceptionally difficult one. Her son was born legally blind and came home on oxygen just five months after Melissa started dialysis. She began her dialysis treatments at a clinic while trying to care for her newborn son, so when a nurse suggested home hemodialysis, Melissa jumped at the opportunity to become more self-sufficient. After six weeks of extensive training, Melissa was able to set up a machine in her bedroom and dialyzed on her own every other night for eight hours while she slept. There was no stopping this determined person.

Incredibly, during this time, she decided to take up the fight against kidney disease on behalf of others like herself. While maintaining a full-time job and raising three wonderful children, Melissa did not let the stringent dialysis schedule or lack of energy keep her from advocating for her cause. She held fundraisers and spoke publicly about her experience in order to promote awareness about kidney disease and people living on dialysis. And for this wonderful person, some wonderful news was on the way.

On April 16, 2012, Melissa awoke to a 3:00am phone call from her doctor informing her that a kidney match had been found. Just two months before her 10-year anniversary of starting dialysis

and being placed on a kidney waiting list, Melissa received a kidney from a deceased donor, giving her a chance for a new life.

Nearly four years' post-transplant, Melissa's kidney is fully functioning and she has never felt better. And that "to-do list" isn't nearly done. Melissa's passion and commitment to patient advocacy and public education is even more revived since receiving the "gift of life." Remaining involved as an active member of the NKF's Kidney Advocacy Committee (KAC) and Advisory Board fulfills Melissa's pursuit of putting kidney disease on the "done list."

...putting kidney disease on the "done list."

Not a Cure but Closer....



*NKF Research Program:
Over \$100 million to 1,000+
researchers for more than 40 years*

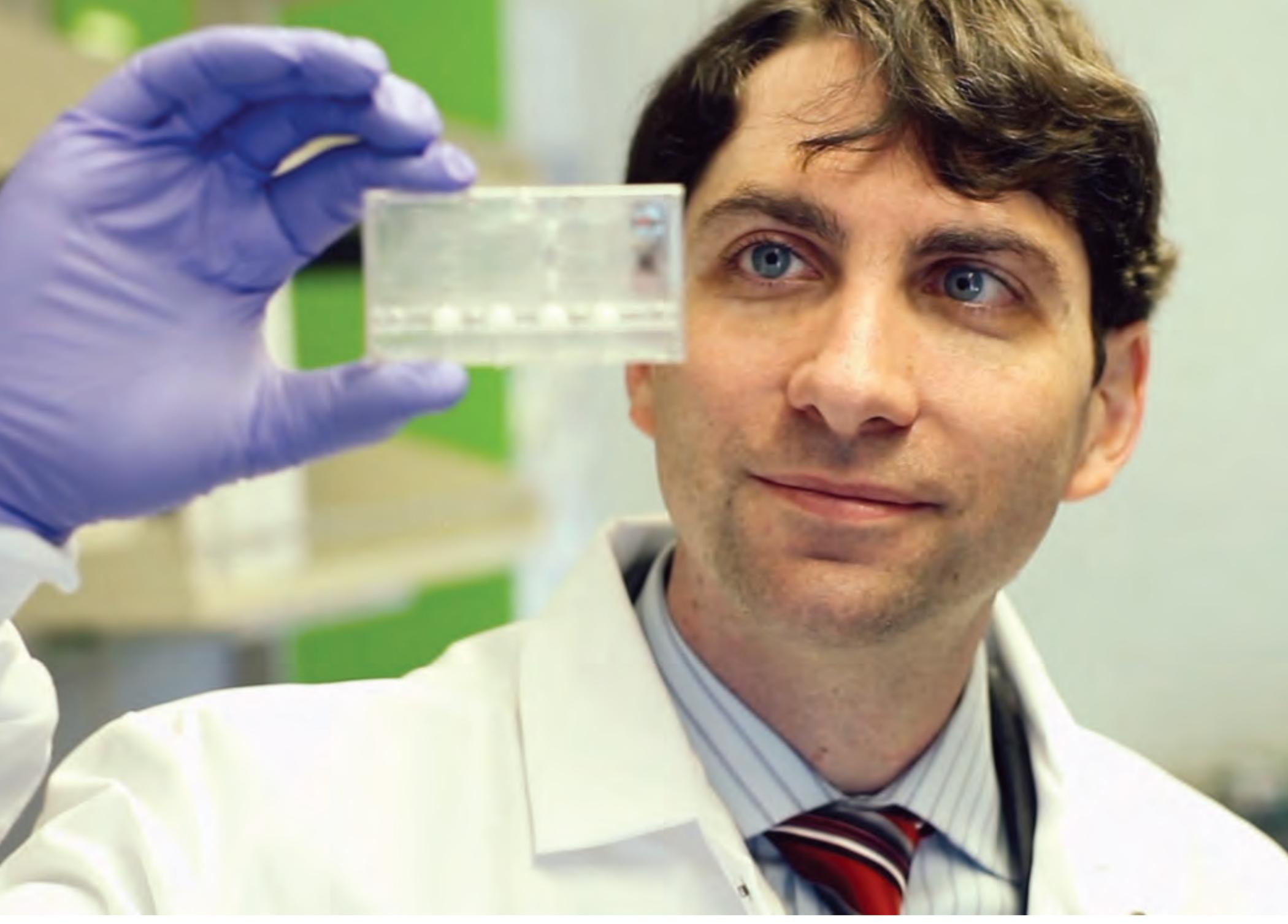
Research is hope in action. Kidney disease was once solely classified as a fatal illness. During the 1960s it was “upgraded” to a chronic illness, not a perfect-world solution, but a step in the right direction. What caused this change? The discovery that certain corticosteroids can bring about remission of nephrosis, the invention of the Teflon shunt that made repeated access to blood vessels for dialysis treatment possible, and the first kidney transplants between siblings. These innovations saved and improved millions of lives. Research drove these initial advances and continues to improve and refine treatment to this day.

The Foundation’s basis is in research. All of NKF’s efforts to help people are supported, directly or indirectly, by research. Our awareness message of early detection and treatment leading to better outcomes is supported by studies of patient data. When we advocate in government for better Medicare coverage or more overall research funding, we do so supported by a brief of patient and scientific studies.

NKF’s Scientific Advisory Board (SAB), comprising leading physicians, scientists and other health professionals, provides vision and direction for our research programs.

The **Young Investigator Awards** are a special category of grants that invest in both the research—and the researcher. Future improvements in the treatment and prevention of kidney disease rest on new investigators just starting their work. By assisting these young medical scientists at a point in their careers when obtaining funding is often difficult, NKF is making an important investment in the future of the scientific community dedicated to kidney research.

The simple principle behind this strategy: If you fund one research project, you will have results in that particular area. However, if you fund beginning researchers, encouraging them to work in the field, you are potentially backing a lifetime of discoveries and progress in treatment.



FY16 Research Grant Recipients

Following are lay summaries of some of our most recent grant recipients:

YOUNG INVESTIGATOR GRANTS

Project: Depicting Glomerular Cell Crosstalk in Glomerulosclerosis

Ilse Daehn, PhD, Icahn School of Medicine at Mount Sinai, New York, NY

Most CKD cases are caused by glomerular diseases, which affect the tiny filtering units within the kidneys. Ilse Daehn and her team developed a unique animal model with the aim of defining **cell-type specific responses of disease progression in CKD**. Specifically, these experiments will identify cellular signaling pathways involved in the crosstalk between glomerular cells, using a large-scale study that looks at the genes being actively expressed in the early stage of the disease (transcriptomics). In the long term, **these studies should lead to a better understanding of the cell damage mechanisms that promote progression of CKD in humans and to potential therapies.**

Project: Modeling PKD Using Genome Editing in Human iPSCs

Benjamin Freedman, PhD, University of Washington School of Medicine, Seattle, WA

Polycystic kidney disease (PKD) is a common, uncured cause of chronic kidney disease in which balloon-like cysts overgrow the kidney. PKD is also associated with high blood pressure and potentially fatal brain aneurysms. Induced pluripotent stem cells (iPSCs) from patients have dual value as personalized laboratory disease models and as a potential source of immunocompatible replacement tissue. Benjamin Freedman and colleagues recently discovered a disease-related defect at a cellular “antenna” called a cilium in iPSCs from PKD patients. Using a new gene editing technique that allows us to “cut and paste” DNA into cells, we will correct the DNA of our existing PKD iPSCs or create new mutations. Dr. Freedman will carefully examine these cells in 2D and 3D to **understand how cysts and aneurysms arise in patients and to test gene therapy.** This will also advance our ability to design custom kidneys that would be 100 percent immunocompatible with patients.

Project: Sleep Restriction and Renal Function

Ciaran McMullan, MD, Brigham and Women’s Hospital, Boston, MA

Kidney function is regulated by the sleep-wake cycle. Coordination of this periodicity in the kidney permits anticipation of the metabolic and physiological demands of the kidney throughout a 24-hour cycle. Although sleep disruption has been studied extensively in cardiovascular and metabolic disease, its association with CKD has not been studied. Furthermore, low levels of the “night-time” hormone melatonin have been associated with many conditions related to CKD, including hypertension, diabetes, and systemic inflammation, yet the benefits of increasing melatonin levels on the risk for chronic kidney disease is unknown. We aim **to investigate the effect of repetitive sleep restriction and shift work on risk factors for CKD and the effect of sleep extension and melatonin supplementation on CKD risk factors among individuals at increased risk** for the development of CKD. (See page 30 for profile.)

Project: Dynamics of H₂O₂ Release in Salt-Sensitive Hypertension

Oleg Palygin, PhD, Medical College of Wisconsin, Milwaukee, WI

This project will focus on **the role played by H₂O₂ (hydrogen peroxide) in the development of hypertension.** Specifically, this study will define the role of NADPH (nicotinamide adenine dinucleotide phosphate, reduced form) oxidase subunits Nox4 (a hydrogen peroxide generating oxygen sensor) and p67phox (a signaler and cell protein) in the **H₂O₂ release in the kidney during the development of salt-sensitive hypertension.** Basal levels and real-time dynamic changes of H₂O₂ will be determined in vivo using a novel approach developed by the applicant based on the use of enzymatic biosensors. The project will result in basic knowledge of molecular mechanisms involved in the development of hypertension and chronic kidney diseases. Elucidation of the interaction between specific NADPH subunits and Ang II (Angiotensin II) will advance our understanding of the basic mechanisms mediating salt-dependent forms of hypertension and provide novel targets and strategies for their treatment. Development of this **unique method, which allows real-time measurements of endogenous substances in the kidney, could be further applied for basic and translational studies.**



National Young Investigator Forum participants: (Left to Right) Mark Sarnak, MD – Evan C. Ray, MD, PhD – Michelle O'Shaughnessy, MD – Lauren Beach, JD, PhD – Jordana Cohen, MD, MSCE – Jamie Lin, MD – Orhan Efe, MD – Joseph V. Bonventre, MD, PhD.



Katherine Lynch, MD

SATELLITE DIALYSIS CLINICAL INVESTIGATOR GRANT

Project: Olfaction and Taste in Chronic Kidney Disease

Katherine Lynch, MD, Beth Israel Deaconess Medical Center, Boston, MA

Malnutrition is an important complication of advanced CKD, and impairment in smell and taste may affect nutritional status. Impairments in smell and taste have been linked with decreased appetite and food intake and can decrease the quality of life for affected patients. The ability to smell and taste declines with age, but patients with **CKD have earlier and greater decline in these senses than patients without kidney disease.** This study will examine how impairment in smell and/or taste is linked with markers of nutrition such as lean body weight and functional markers such as hand strength and patient-reported functional ability. **We also seek to identify potentially modifiable risk factors for smell and taste impairment,** which may eventually allow for treatment and improvement in smell and taste.





CIARAN MCMULLAN, MD

Sleeplessness Study Wakes Up People about Impact on Kidney Health

So much to do, so little time.... Many of us “solve” that problem by cutting back on our sleep—and it’s not a good solution. The Centers for Disease Control and Prevention recently declared sleeplessness a public health epidemic.*

Researchers have already linked sleep deprivation and sleep disorders to higher rates of diabetes and cardiovascular disease, and now the link between shut-eye and kidney function is becoming clearer with new research by **Ciaran McMullan, MD, of Brigham and Women’s Hospital.**

With the support of a **Young Investigators Grant from the NKF**, Dr. McMullan is studying how sleep affects the kidneys and whether more sleep and melatonin supplementation can improve kidney function.

“Kidney function is actually regulated by the sleep-wake cycle. It helps coordinate the kidneys’ workload over 24 hours,” Dr. McMullan said. “We also know that nocturnal patterns can affect chronic kidney disease and that people who sleep less usually have faster kidney function decline. What we’re doing now is looking at the specific hormones that may be behind these declines.”

Dr. McMullan’s research will take a closer look at melatonin secretion, which is the hormone our bodies produce naturally to synch our nocturnal functions. As part of the study, healthy participants will have their sleep restricted and their hormone levels and kidney function measured.

The study will also include people who are habitually sleep restricted and will ask them to sleep longer hours to see if that affects their physiology, blood pressure, blood glucose levels and kidney function. Half of this group will also be given melatonin supplements to see if that has an impact on their kidney function over time. “So not only are we looking at people’s sleep patterns, we’re trying to see if there may be some interventions that can be taken by people with sleep deprivation,” Dr. McMullan said.

Better understanding how the kidneys work and interact with our hormones at night might also help determine better nutrition guidelines and optimized times for medication delivery. This is because

the kidneys’ ability to process medications and nutrients like sodium and potassium changes between day and night.

The study could identify new groups of people who are at higher risk for developing chronic kidney disease because of their lifestyle or work schedule, for example, those who work in shifts and those with chronic sleep deprivation issues.

“It pays to recognize these issues as risk factors because it means these individuals may need more aggressive kidney disease screening and blood pressure management,” McMullan said.

*<https://www.uvmc.com/About-Us/News-Center/Press-Releases/Sleeplessness-Declared-Public-Health-Epidemic-in-America>

Our founder Ada DeBold began this organization to seek a cure for her son. The search continues for a definitive treatment, but astonishing recent breakthroughs offer hope for millions, including research on tissue engineering to “custom grow” new kidneys in the lab for recipients.*

Additionally, the *New England Journal of Medicine* published a study in March 2016 of a breakthrough procedure to alter patients’ immune systems to stop rejection of transplanted organs. This indicates that in the future “anyone could donate a kidney to anyone,” no longer necessitating years on the kidney transplant waiting list. Dr. Jeffrey Berns, President of NKF, commented to *The New York Times* that this procedure “has the potential to save many lives.”

Thanks to ongoing research, “they’re working on a cure” is no longer a cliché or an abstract consolation for patients, but action producing substantive results. With the worldwide increase in kidney disease resulting from rising rates of diabetes, high blood pressure, and obesity, investment in research has become more urgent than ever.

*<https://www.theguardian.com/science/2013/apr/14/kidney-grown-lab-transplanted-animal>





In First Person:

A Person with Kidney Disease Speaks to You

Sonya Cochran
Stillwell, OK

***M**y name is Sonya, and I have been married to my husband Martin for 23 years. In 1993, I was diagnosed with IGA nephropathy and began dialysis in 1996. After beginning dialysis, I was very emotional and cried during several of my treatments. If it wasn't for my faith in God and the support of my husband and family, I wouldn't have overcome the difficulty of knowing I had to be on dialysis for the rest of my life.*

After several months of being on dialysis, I began doing research on my family history and found the disease was hereditary on my father's side. My grandfather and uncle passed away due to this disease. At that point, I began to educate my family and friends about

staying healthy, getting yearly checkups, and knowing the signs and symptoms of renal failure and [about] kidney care.

I didn't want dialysis to stop me from living my life, so I began taking college courses and received my bachelor's degree in Social Work. While attending college, I was able to volunteer at our local food pantry and educate participants about having a healthy lifestyle. In 2001, I received the call every person on the transplant list hopes for, and I was blessed to receive a kidney from a deceased donor. Two months after receiving my kidney, I began the master's program at the University of Oklahoma and eventually received my master's degree in Social Work. I started working for my Native American tribe as a social

worker for victims of violent crimes, and I continued to advocate for kidney care by contacting our state representative and Congress concerning policy changes.

After seven years of having a transplant, the disease came back and affected my kidney, and I eventually had to be back on dialysis. I am thankful for the time that I had my donated kidney and am very appreciative to anyone [who] is an organ and tissue donor.

I continue to raise awareness about kidney disease. I also strongly believe being on dialysis is not the end of life; it's making adjustments to your daily schedule. I continue to work and volunteer. I am on the food pantry board which meets on a monthly basis. I assist with emergencies when needed, conduct

and participate in numerous church activities, serve as chairperson [for an emergency assistance fund], assist with the community board members, assist college students in filling out scholarships, attend training for my job, do house duties, support my niece and nephews in all their events, attend all my siblings' events, and attend my church on a regular basis. It was this year that I became a member of the NKF Kidney Advocacy Committee, and I am very excited about this opportunity. I hope I can continue to educate others about the importance of kidney care. I am thankful to my husband, family and, most importantly, to my God; through him all things are possible.

Sonya Cochran

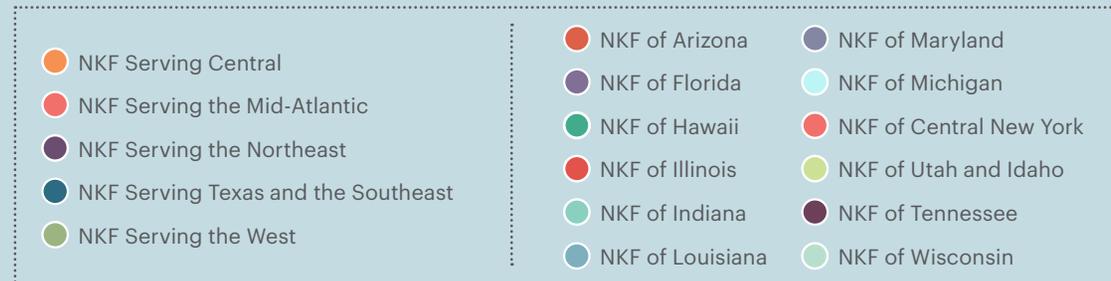
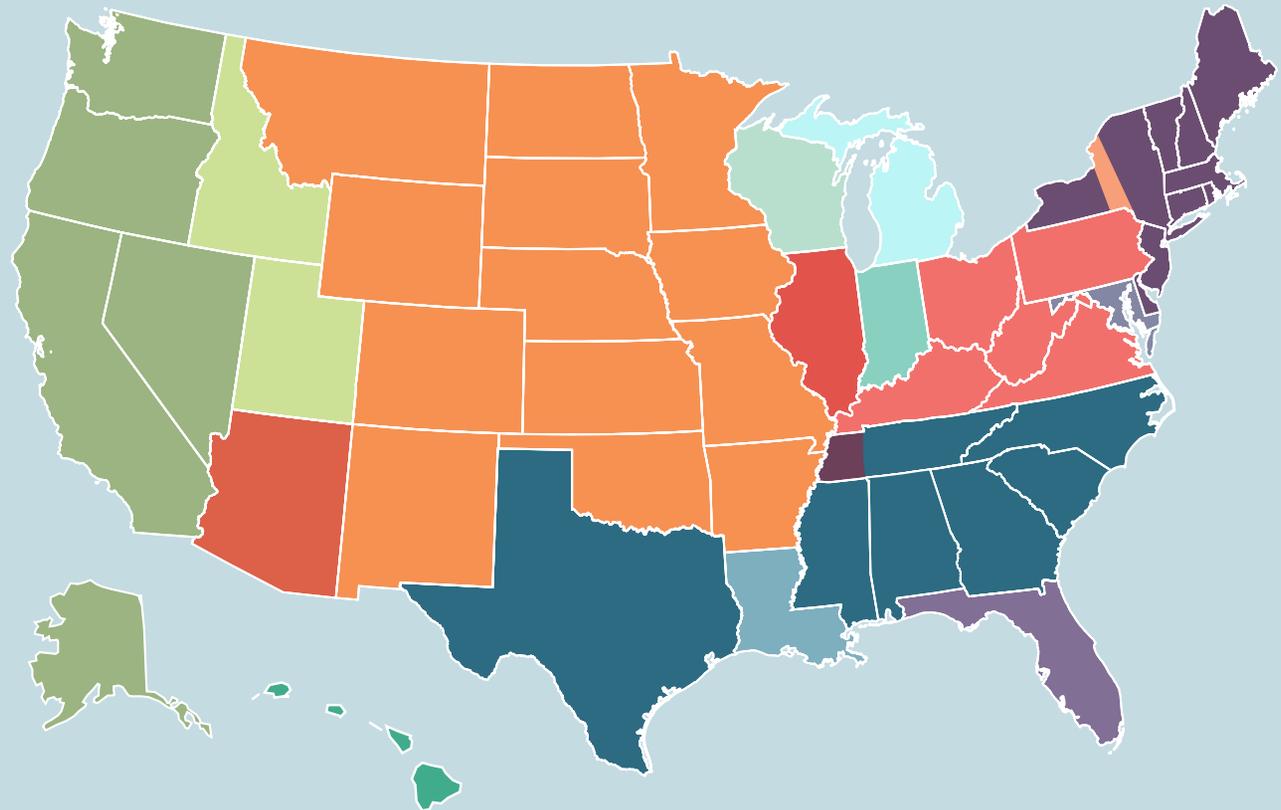
" I began to educate my family and friends about staying healthy, getting yearly checkups, and knowing the signs and symptoms of renal failure and [about] kidney care. "

Reaching Out Across the Country....

National” means “local.” It means being an active, on-the-spot presence accessible to people with kidney disease across the country. Local offices provide services to people in the surrounding areas and also work to support our mission nationally. Each region has its own challenges and opportunities. The quality and accessibility of healthcare, local government responsiveness, demographics, and population concentrations vary widely between areas. The one thing that is consistent is kidney disease—and the need for NKF to help. The people at NKF local offices are mission-oriented, dedicated, and work very hard for our constituents. They are the faces of our organization for kidney patients and their caregivers throughout the country.

On the move across the country for people with kidney disease: Highlights of Local Offices, People, and Events

These highlights are just examples of the constant work going on in our local offices. Together they form a picture of NKF at work across the country.



NKF Serving the Northeast

New York, NY—After decades of suffering from CKD and surviving non-Hodgkin’s lymphoma, Fiona Portington’s mother received a kidney transplant from Fiona’s father in May 2015. Like many with a personal connection to kidney disease and who want to do something about it, Fiona became one of our newest local board members. Professionally, Fiona is a derivatives trader for J.P. Morgan. By sharing her story, she secured a record \$70,000 at our **Gift of Life Auction during our 10th Annual Springtime in New York Gala.**



New York, NY—Meredith J. Aull, PharmD, Associate Research Professor of Pharmacology in Surgery at Weill Cornell Medical College, raised more than \$40,000 for the NYC Kidney Walk, via New York Presbyterian/Weill Cornell and

her network of contacts. She does this to raise money for her patients, and especially for a personal friend who is on the kidney transplant waiting list. She also runs in the **United Arab Emirates Healthy Kidney Race.** Besides treating and raising support for her patients, she was also a speaker at our **professional education accredited symposium “Special Populations: What Shall We Do?”** on the topic “To Treat or Not to Treat: Should We Wait Until After Kidney Transplantation to Attempt to Cure Hepatitis C?”



Bronx, NY—NKF of Greater New York (GNY) was the first to launch the new **CKDinform program** (see page 3). The first CKDinform one-hour presentation was held at Lincoln Medical and Mental Health Center. From September through March,

GNY presented 11 programs at many other locations—three stand-alone events with the American College of Physicians, seven Grand Rounds at area hospitals, and one three-hour symposium at the 1199 Renal Day event for the United Healthcare Workers East. The total number of attendees for all presentations was 1559.

Huntington Station, NY—Chris Melz has an unusual story—from DJ to RN! **He donated a kidney to a childhood friend with diabetes eight years ago.** Originally a well-known DJ, his experience with kidney donation inspired him to change careers and become a nurse! (See Chris’ story on page 14.)

Rochester, NY—NKF has a ticket to ride in Rochester! NKF Serving Upstate and Western New York secured an in-kind donation of **15 huge signs** (valued at more than \$14,000) on **Rochester Regional Transit Buses.** Two months of marketing was donated by Lamar Advertising. The advertising started running on National Kidney Month in March 2016 and ran through April. It was displayed on 15 RTS buses on routes throughout Downtown Rochester.



Monroe County, NY—The local NKF is constantly approached by CKD and end-stage renal disease patients for nutrition education. To address this critical need, in March 2016 a seminar, “**Nutrition for Chronic Kidney Disease, Diabetes and Hypertension: Treatment through Diet,**” was created specifically for patients, their caregivers, and people living with diabetes and hypertension. The program focused on providing direct dietary education and hands-on health management experience to a targeted **audience of 60 patients and caregivers in Monroe County.** **Twelve local project partners** collaborated on the project and contributed \$4,500 in sponsorships to cover costs.

Buffalo, NY—The 11th Annual Joint Meeting of the Upstate and WNY NKF Councils on Renal Nutrition: This daylong symposium provided **continuing professional education** for 150 dietitians, dietetic technicians, and nurses on CKD treatment and interventions to delay progression. Topics at the daylong symposium included emerging research about prevention of cardiovascular disease, CKD risk awareness and risk prevention, transplant and diet, probiotics, and facilitating patient behavioral change. These topics are particularly relevant to midlevel providers. The program also raised grant support, sponsorships, and registration fees.



Boston, MA—In its fourth year, the local **NKF Golf Classic**, chaired by Alex Wayman, teed off in June at the Boston Golf Club, raising more than \$100,000. Local sponsors included Putnam Investments, Grey Goose, BMW, and *Boston Common* magazine.

NKF Celebrates! Held on World Kidney Day at Boston’s Museum of Science, this inaugural event celebrated the impact of NKF leadership and funding in New England and raised awareness on the importance of living donation. **The NKF Hero Award** was presented to living kidney donor Diane Kelly. The event also highlighted the exceptional work of **NKF Young Investigator** Ciaran McMullan, MD, of the Brigham and Women’s Hospital. (See page 30.)



MA, RI, and ME—NKF Serving New England reached out across three states, holding **KEEP Healthy events and Your Kidneys and You programs**. More than 160 people were tested for kidney disease risk factors and more than 400 people educated about the importance of kidney health. In addition, nephrologists from 12 major hospitals who serve on **NKF Serving New England’s Medical Advisory Board** work to provide the best patient and professional education, **organizing Inter-Hospital Renal Rounds** with 119 fellows and nephrologists in attendance. **The Council on Renal Nutrition and the Council of Nephrology Social Workers** organized three conferences providing continuing education to more than 130 healthcare professionals.



Cleveland, OH—NKF Serving the Mid-Atlantic held its inaugural **Patient Symposium in Cleveland**. The event was a **free day of education for patients and caregivers** and raised \$18,000 from donors. Local board member Dr. Rupesh Raina served as the event’s chairman.

The **Northeast Ohio Kidney Walk**, locally presented by the Glickman Urological and Kidney Institute at the Cleveland Clinic, enjoyed the 10th largest net revenue of all of the Walks in the country supporting NKF initiatives and programs.

Cleveland held its first Dining with the Stars event in which 22 local restaurants paired with 22 local celebrities. There were more than 250 guests and \$12,000 was raised the night of the event in the “Mission Moment.”



NKF Serving Ohio and Kentucky felt that despite all of the business related to kidney disease in northeast Ohio, there was something missing. Patients were constantly calling asking where they might find a local support group. The staff knew from these calls and from research that there has been a deficiency of such meetings. To answer this need, the Cleveland office organized the **first Patient Symposium** on October 18, 2015, where patients and caregivers gathered at MetroHealth Hospital for a Sunday afternoon. They had **panels of experts and break-out sessions with specific topics addressing the most common patient concerns.** The goal of the Patient Symposium was to empower patients and caregivers and allow them the opportunity to meet other individuals who have the same concerns. It was very well received and the second event will take place on October 23, 2016.

Philadelphia, PA—In July 2015 the Delaware Valley’s Eighth Annual Mid-Atlantic First Year Renal Fellow’s Symposium provided **two days of intensive education**

to 36 new renal fellows from 14 institutions within a three-hour radius of Philadelphia. These fellows benefited from the wide scope of this program that helped them to start their renal fellowship. The faculty for the program included 24 physicians. A renal biopsy simulation was included on the second day.



Washington, D.C.—NKF Serving the National Capital Area kicked off 2016 by **screening more than 600 people** for kidney disease at the NBC4 Health and Fitness Expo, held at the Walter E. Washington Convention Center. **A team of seven staff members and 50 volunteers worked tirelessly over two days to deliver NKF’s signature KEEP Healthy program to Expo attendees,** with a focus on increasing awareness of risk factors and kidney

disease education. “Everyone was very helpful and informative,” one patient wrote on a post-screening evaluation form. “I felt very comfortable with the treatment I received. The doctor I spoke with was very nice and knowledgeable. He helped me understand the importance of taking care of my kidneys.”

The Masquerade Kidney Ball celebrated 35 years as the nation’s largest black-tie gala for kidney disease on October 24, 2015 at the historic Omni Shoreham Hotel. **The gala convened nearly 700 of the Washington, D.C. area’s top business, government and community leaders, as well as kidney patients and their families,** and raised more than \$600,000 for the Foundation. The program featured an awards presentation that honored some of the region’s most dedicated supporters, including Steve Kahn, who helped launch the National Capital Area’s major gifts program and who served as chairman of both the Kidney Ball and National Capital Area’s local advisory board. Steve became involved with NKF after his wife

Toby was diagnosed with kidney disease in 1986, and he became her living donor in 2002.

On March 14, 2016, **the National Capital Area hosted its third annual Congressional Dinner event honoring Sen. Richard Burr (R-NC) and Rep. John Lewis (D-5th GA)** for their support of legislative policies relevant to the millions of Americans affected by kidney disease and organ transplantation. **Former Secretary of Health and Human Services and Wisconsin Governor Tommy Thompson chaired the event,** which raised \$77,000 for NKF.



Steve Kahn at the Masquerade Kidney Ball.

NKF of Maryland

Alleghenies—NKF Serving the **Alleghenies** worked with its **Multicultural Task Force** to reach the area’s at-risk and underserved communities. It **provided awareness messaging to 335 people** through Your Kidneys and You presentations and **screened 319 through KEEP Healthy**. In addition, the local **Medical Advisory Board launched a nephrology networking series** that encourages regional nephrologists to share interesting cases and new ideas. As a provider for the Pennsylvania Department of Health Chronic Renal Disease Program (CRDP) Transportation Program, **NKF Serving the Alleghenies administered \$433,000 in transportation reimbursement to more than 800 dialysis patients**. These patients must be active members of CRDP and meet the eligibility guidelines determined by the CRDP.

The **National Kidney Foundation of Maryland** understands the sometimes desperate life situations that develop for people with CKD: *Mr. Harper, who lives independently on a modest income, is a kidney dialysis patient confined to a wheelchair. He lives in Section 8 subsidized public housing, and his rent was increased from \$181 to \$242 monthly, creating a financial burden. This led to his accumulating a large utility bill, and he would forgo eating to pay for transportation to lifesaving dialysis. NKF of Maryland was able to alleviate this situation through its **Patient Emergency Assistance Program**.*

In 2014–2015, NKF of MD granted a total of \$150,000 to nearly 1,000 patients with similar needs as part of its **Patient Emergency Assistance Program** to meet urgent needs including rent, utilities, transportation, medical, and dental support. Dealing with kidney disease is enough of a crisis on its own, and people should not have additional burdens.

NKF Serving Central

The Central Region is expanding in 2016. With new activities going on in Albuquerque, NM, Oklahoma City, OK, Columbia, MO, Wichita, KS and Jonesboro, AR, they are poised to affect more lives, in more cities, than ever. They also brought on new staff to serve Sioux Falls, SD, and Wichita, KS.

St. Louis and Denver—NKF Central **launched a new patient education program** called “**Kidney Care Kits**.” **This program delivers patient-centric KLS education material straight to patients** through their physicians. It’s stage-specific and outcomes-driven, so each patient gets information customized to their particular situation. **The Iowa and Nebraska office also launched a new patient education program called the Kidney Resource Center**, which is a freestanding display tower that presents a comprehensive suite of KLS educational tools directly to patients at their doctors’ offices.

St. Louis—The St. Louis office held **their very first full three-hour CKDinform symposium** in the county. This event hosted 59 physicians and allied healthcare

professionals where they learned the importance of early identification and delayed progression of CKD in their at-risk patients.

NKF of Wisconsin

The **National Kidney Foundation of Wisconsin (NKF)** believes that food pantries are important partners in healthy eating and can help prevent chronic conditions like kidney disease.

NKF is a founding member organization of Wisconsin’s **Healthy Shelves**, a workplace and community education effort dedicated to filling the shelves of Wisconsin food pantries with nutritional products.

NKF is partnering on its **Healthy Shelves** work with Mount Mary University’s Department of Dietetics and the FoodWise program of the University of Wisconsin Extension.

Healthy Shelves also offers employers, faith-based communities, schools, and community leaders engaged in food distribution programs free materials, a website, and logistical assistance, so that they can all “skip the mac ‘n’ cheese.”

NKF of Illinois

From the **National Kidney Foundation of Illinois (NKFI)**

Affiliate: José is a 26-year-old Latino man with a bit of a weight problem, but no other health concerns. When he saw the notice offering free screening for kidney disease, diabetes, and high blood pressure [a KEEP Healthy event], he thought, “What the heck?” That casual decision saved his life.

José went through the screening, and two very simple tests indicated that he was a diabetic, and diabetes is the leading cause of kidney disease. The results were so disturbing, our staff urged him to immediately go to the emergency room. When we followed up with him the next day, the doctors had confirmed his diabetes, treated him for more than 10 hours and released him with a referral for additional care. Today, his disease is under control and he is lucky to be living a normal life.

There are hundreds of thousands of people like José in Illinois. NKFI strives every day to reach them, as they did José, before it is too late.

NKF Serving Texas and the Southeast

Texas—The North/West Texas office is most proud of its KEEP events.

It screened 1,447 people during the year. The average number of people at each event was 160. It is grateful to all of its volunteers who helped make those numbers possible

The Southeast Texas office relocated in 2015 and added a Development Manager and Development Coordinator to its permanent staff. It received a \$150,000 grant from H-E-B, its first major awareness partner, allowing it to continue to promote kidney health via its relationship with the retailer’s on-site pharmacists, as well as other initiatives.

The South Central Texas office opened in 2015 in Austin and engaged with LogistiCare as a major partner in expanding the NKF’s presence and outreach in the community while laying the groundwork for elevated advocacy for kidney patients in the capital city.

Southeast—The Southeast Region developed a strategic partnership with Omega Psi Phi, an international fraternity with more than 750 undergraduate and graduate chapters and the first predominantly African-American fraternity to be founded at a historical black college and university. The partnership provides KEEP Healthy screenings at fraternal events and is training OPP members to provide Your Kidneys and You presentations throughout the Southeast.



NKF Serving the West

California—Robin Pearson and Sheila FitzPatrick, members of the local advisory board in Northern California, expressed interest in hosting an event that provided resources and education about transplantation to patients. The field office shared their interest, and the first annual Northern California Patient Symposium was born. More than 70 attendees gathered at the inaugural symposium to hear the heads of the transplant programs of four major hospitals discuss patient care options and recent advancements. NKF empowered many people to be better informed about their treatment options.





It's Our Challenge:

Advocacy for One Child—and the World

Kelly Cline
Glen Allen, VA

People react differently to crises. For some, a crisis is not only a situation to be faced and managed, but it is also a turning point, an engine of change. Parents of children with life-threatening diseases and conditions learn advocacy overnight. From the moment a serious condition is diagnosed in their child they are transformed from a regular, loving parent to a determined, medically savvy advocate who champions their child's cause. For Virginia advocate Kelly Cline, her story with kidney disease began when her 13-month-old daughter Hannah was diagnosed with Wilms' tumor, a cancer affecting the kidneys.

Hannah had her left kidney removed and was treated with chemotherapy. Another crisis came soon after. When Hannah was 23 months old, tests showed suspicious "nephrogenic rests" in her right kidney. Rests are leftover embryonic tissue and a precursor to Wilms' tumor. Her right kidney was operated on to remove them and reduced her kidney

function to about 75 percent. Later that year it was discovered that she had focal segmental glomerulosclerosis (FSGS) in her remaining right kidney as well. FSGS is selective scarring of the functional parts of kidney tissue. Hannah fought the kidney disease until 2011 when her kidney failed.

To say the least, Hannah was having a rough time, but she had one advantage. Her parents were willing to go to any lengths to save and improve her life.

She received a living donor transplant from her dad, Chris Shelton, in September 2011 when she was 11 years old. She is now 15 and doing well!

Kelly Cline was there with her daughter, side-by-side, giving support, strength, whatever was needed. Kidney disease became her personal nemesis, something attacking her daughter and to be fought against—hard.

Kelly thought of the other mothers and parents—and children—out there undergoing the same ordeal, and

decided to act on the problem. Through NKF, she became involved in the fight against kidney disease on a larger scale. She attended the Kidney Summit in Washington, D.C., during Kidney Month in March 2014 and had the opportunity to speak with senators and representatives, sharing her personal story and explaining why their support for kidney disease was urgently needed. Kelly, one of NKF's most active Kidney Advocacy Committee (KAC) members, is planning more trips to Washington to work with her representatives to enact legislation regarding the importance of living organ donation. As a member of KAC, Kelly focuses on living donation, the process that saved Hannah's life, and is a staunch supporter of the Living Donor Protection Act (LDPA) (H.R.4616/S.2584).

Kelly's involvement with NKF doesn't stop at advocacy. She's also actively involved with raising support for NKF through NKF Walk and Golf events. In 2013 and 2014, Kelly participated in

the Richmond, VA, Kidney Walk and was a top fundraiser. Her Walk Team is called "Hannah's Heroes," named for her daughter. She is looking forward to making the team even larger this year and hopes to work on the Kidney Walk Planning Committee for Richmond.

Kelly's energy seems boundless. In 2014, she spoke at the Richmond NKF Golf Tournament about her daughter's experience with kidney disease and how it has affected her whole family.

Hannah and Kelly's story reminds us of NKF founder Ada DeBold's work for her son. Fortunately, so far, this story has a happier resolution. But there are other stories out there whose outcome depends on NKF's continuing work. Her experiences through Hannah have given Kelly a passion to help others in the same situation or, better yet, to educate those who still have the opportunity to avoid going through the trials and challenges of kidney disease.

... transformed from a regular, loving parent to a determined, medically savvy advocate ...

Talking to Each Other Across the Country: Board-to-Board Communication

Effectively serving patients, families and healthcare professionals means keeping each other “in the loop” about what’s going on. Efficiency within any organization is about communication, so that the best possible ideas and solutions

are available to everyone, and work is not needlessly duplicated. With that in mind, NKF has developed a structured **program to communicate with our local boards, NKF Board-to-Board (B2B)**. The centerpiece of this program is a quarterly report/e-newsletter from NKF’s Executive Leadership to our 25 local boards across the country on major initiatives, events,

and accomplishments in advocacy, research, and other areas of interest.

“Local” does mean “national” in terms of NKF being a nationwide support network, and in terms of local work collectively supporting our overall mission for patients.

As a national organization, to enact major changes in the lives of people affected

by kidney disease, NKF accesses the power of government. NKF transforms the national landscape and the culture of treatment, care, and research to benefit patients and families across the country by “writing our mission into law” through Congress...

Government Advocacy: The Biggest Engine of Change

It’s about plans on paper becoming actions and producing change. Action by the federal government can build projects on the scale of the National Highway System or landing a man on the moon and enact national programs like Medicare and the Affordable Care Act. Harnessing and influencing this broadscale power have huge potential to change lives. Even small measures can ripple outward across the country, improving hundreds of thousands of lives. **Government advocacy** has been a mission mainstay since our beginning when NKF advocated for, and participated in, the drafting and passing of the **1968 Uniform Anatomical Gift Act, which established regulations for organ and tissue donation**. NKF was also the leading force behind legislation in 1972 that created **Medicare’s End-Stage Renal Disease Program**, which remains the only Medicare benefit based on disease rather than age or disability (SSDI) status. Since then, from

protecting kidney patients’ Medicaid coverage to funding research, NKF has been the voice of patients and families in Congress. More recently, we helped pass legislation that cleared the way for kidney paired donation, which helped dramatically increase opportunities for living kidney donation.

In addition to the introduction of the Living Donor Protection Act (H.R. 4616/ S. 2584) (see page 8), **FY16 Public policy activities include:**

In alignment with **the CKDintercept initiative**, NKF is recommending to Congress and the Centers for Medicare and Medicaid Services (CMS) **a new payment model that encourages healthcare professionals to improve early detection** of CKD, including follow-up care. NKF Advocacy convened a National Workgroup to develop a payment model that can be tested by CMS and other healthcare payers.

NKF also **worked with the U.S. Department of Health and Human Services (DHHS), CMS,** and state insurance commissioners

to ensure that kidney patients who have private health insurance coverage have access to medications, kidney transplants, and dialysis.

NKF is **collaborating with the National Health Council to create guidelines for the Food and Drug Administration (FDA) on patient input** into drug development.

NKF is very **active in coalition and alliance activities** to expand support for the needs of our constituents. We are a member of the Friends of NIDDK (National Institute of Diabetes and Digestive and Kidney Diseases) Steering Committee, the Alliance for a Stronger FDA Board of Directors, the Alliance for Home Dialysis Steering Committee, and the National Health Council as a co-chair of its Health Care Reform Action Team and a member of its Public Policy Action Team, among many other coalitions. **By speaking as one voice we can build support** for multiple public policy activities.

Kidney disease is a rising national problem. Federal legislation means



sweeping change. The match is there, of problem and solution. NKF is striving to work hand-in-hand with our government to make kidney disease a national priority and to develop and enact solutions on a national scale.

Patients and Families: Essential to Our Team and Making the Mission Happen

Who can speak better about the experience of living with kidney disease than the patients themselves and their caregivers? Who can better know their needs and issues?

With the help of NKF, kidney patients “went to Washington” with the Kidney Patient Summit.

More than 100 patient advocates and family members, representing 44 states (including Alaska and Hawaii) and the District of Columbia, joined with NKF, Alport Syndrome Foundation, American Association of Kidney Patients, NephCure Kidney International, and the PKD Foundation to reinforce the message that “Kidney Disease is a National Healthcare Priority” at the third Kidney Patient Summit in Washington, D.C. This annual event jumpstarted **National Kidney Month**, and participants attended **more than 175 congressional meetings, including 14 face-to-face meetings with senators.**

The Kidney Advocacy Committee (KAC) was created in 2015 to strengthen NKF’s visibility as **a leading patient**

advocacy organization, to develop and fortify partnerships with Members of Congress, and to keep the patient perspective first. More than 100 patient liaisons moved on NKF’s strategic plan by submitting letters to the editors of publications around the country, meeting with lawmakers on Capitol Hill and in their home districts, presenting Your Kidneys and You to community groups, becoming trained peer mentors, reviewing publications and web content, representing NKF on external committees and workgroups, and providing input to help construct NKF’s overall patient engagement plan. This powerful entity is an exemplar of our mission at work, actively helping patients.



People support the Foundation because they care about those with kidney disease as much as we do. That's nowhere more evident than in our signature fundraising activity, the **NKF Kidney Walk** program in which 85,000 Walkers—and their supporters—step out in 100+ Walks across the country. Each year, dedicated Kidney Walkers solicit sponsorship from friends, families, co-workers, and local businesses, raising more than \$10 million to fund lifesaving research and awareness and education activities. Since 2008, the Kidney Walks have raised more than \$80 million!

The Walks are always on the move. In the past four years, the Kidney Walk program has added 11 new events across the country, including New Mexico, Las Vegas, and Rhode Island, both as local NKF staff run Walks and volunteer-led efforts. And the Kidney Walk National Partner Program, a sponsorship initiative, has continued to grow 33 percent annually. Kidney Walks do double duty as well, **functioning as both fundraising and community awareness events**. In addition to fundraising, local Walks function as positive, family friendly public rallies, letting each community know about the importance of kidney health, risk reduction, issues needing government advocacy, as well as kidney donation. At most events, educational materials are made available to attendees on the day of the event. And NKF staff members are always glad to answer any questions.

Investing in Now and the Future...

A diagnosis of kidney disease puts people firmly in the “now.” They reach out for help, and we are there for them. But what about the millions of people who have a diagnosis in their future? What can we do for them today? Research, for one thing. Planning for the challenges ahead is another—building the organization to keep it relevant and useful for the people we serve in the future.

Funding builds the future. NKF relies on these **funding sources**: individuals, foundations, corporations, and government grants. Our programs are also supported through **fundraising activities**: contributions (individual giving, memorials, estates, trusts); events (NKF Kidney Walks, NKF Golf Classic, local galas, endurance sports events, do-it-yourself fundraising, and other special events); programs (such as corporate sponsorship of KLS projects); NKF Kidney Cars; thrift stores; employee giving campaigns; and revenue sharing from NKF Affiliates. NKF Kidney Walks, Kidney Cars, and the NKF Golf Classic are our most immediately visible activities that raise funds—and awareness of kidney disease. It is our responsibility to not only **deliver that support to people effectively**, but to also **plan for the challenges ahead** and shape our organization accordingly.



Kidney Walk National Sponsors:

Corporate Partner
Mallinckrodt
Pharmaceuticals

Multi-Market
Fresenius Vascular Care
NxStage Kidney Care
Satellite Healthcare

Teams
Aetna
American Renal Associates
Equus Capital Partners, Ltd.
Fresenius Vascular Care

LogistiCare
Madison Apartment Group
NxStage Kidney Care
Relypsa, Inc.

Satellite Healthcare
Student National
Pharmaceutical Association
(SNPhA)

Our classic fundraising “vehicle” is the NKF Kidney Cars Program, the oldest and most trusted charity car donation program in the country. And Kidney Cars is on the move, growing 30 percent over the fiscal year. Both South Carolina and Virginia brought in more than 1,000 vehicles each. Kidney Cars continues to be a steady source of support for our programs.



The NKF Golf Classic, continues to add prestige and excitement to our fundraising efforts as **The Premier Amateur Golf Event for Charity™**. Golfers and their corporate guests raised more than \$3.5 million to benefit NKF, at more than 30 events taking place at some of the most prestigious golf courses in the United States. The January 2016 **National Finals at Pebble Beach** saw a 54 percent increase in participation with 240 players from local events, along with more than 60 national sponsor participants and their customers enjoying three days of golf at the prestigious Pebble Beach Golf Links, The Links at Spanish Bay, and Spyglass Hill Golf Course. Since its inception, the NKF Golf Classic has raised more than \$100 million.

Golf events benefit both NKF and its supporters. Sponsors use the series to entertain clients at the events and to network with the program’s affluent business and community leaders. CBRE and Skechers joined as national sponsors, alongside longtime national partners Insurance Auto Auctions, HM Insurance Group, Tiffany and Co., *Golf Digest*, PING, and the Greg Norman Collection. Locally, the Westchester, NY event at Winged Foot Golf Club led the way in fundraising, with more than \$336,000 raised. Other top events included those in Lakeland, FL, Philadelphia, Pittsburgh, Boston, Des Moines, Phoenix, and Louisville—all exceeding \$100,000. Following the NKF Golf Classic tradition of playing at top-ranked, prestigious venues in each market, tournaments at East Lake Golf Club in Atlanta, and Firestone Country Club in Akron, OH, were added to the schedule.



*A Living Memory,
A Memorial, A Motivation*

Colette and Riaz Ali
Long Island, NY

Patients and families. That's a phrase we use a lot at NKF. By it we mean that kidney disease affects not only a person but also the people around them, the people who care for them.

For the Ali Family, NKF's mission is a very personal one.

The Ali family lost their 23-year-old daughter, Rasheeda "Amy" Rodriguez, to kidney disease in 2014. It was a shock when she was diagnosed with CKD in 2011 at the age of 21. She had heart palpitations and her husband took her to see a doctor. Her blood pressure was so high that the doctor sent her to the hospital immediately, where tests showed that her kidneys were enlarged and only functioning at 15 percent. She was immediately placed on medication and had to inject herself with it daily. Within a few months, her illness progressed and she was placed on dialysis.

Says her father, "My daughter Amy helped me to deal with it and she helped me to accept it. She taught me how to be strong and be there for her. It was hard for me to come to terms with it."

Amy fought hard for her life, but the disease "took a toll on her body and she had a heart attack," said her father. Two years after the initial diagnosis, Amy lost her fight, but continued to win through her family's actions and memory of her.

Amy's family will not let the disease that took her life *define* her life. This was an outstanding person who had a lot to live for and who made a difference to those around her.

Amy was born on the island of Trinidad and immigrated to New York in 1998 when she was eight years old. Says her father, "My daughter was my gem, my angel, my

love, my all. Amy was a fun-loving, happy child and the strongest person I know. She loved to read—sometimes over 20 books per month! She loved spending time with family and friends and would light up a room with her smile. When she went to dialysis three times a week, she dressed up, did her beautiful hair, which she cherished a lot—she looked like she was going to hang out with friends. Amy lived each day like it was her last—she made the very best of the time she had."

Team Amy is named for a light that went out far too soon.

On the principle that action is the best memorial, thousands of brave families every year move against kidney disease as memorial Walk teams. "We are now indebted to her and keeping her memory alive by supporting this Foundation, in her name, and by bringing awareness

to her peers and others in the kidney community," says her father. The Alis keep Amy's memory alive by acting on the problem that took her away. They work to support NKF so that others will not have a loss like theirs.

The Alis not only participate in the Long Island Walk through Team Amy, they also participate in promotional materials for NKF. It's about keeping Amy's memory alive—by helping to keep others like Amy alive.

Action is the best memorial.

NKF's corporate partners continue to demonstrate their belief that good health is good business by partnering with NKF on our programs. This fiscal year, we launched a brand new **Corporate Membership program** which aims to highlight our most dedicated corporate partners in the fight against kidney disease. The program includes Bronze, Silver, and Gold levels of participation. **The first Annual Corporate Innovator Award** was created to recognize industry partners that advance the field of nephrology by addressing an unmet medical need, or improving upon an existing practice, therapeutic or technology. This year's award was presented to Relypsa.

Who Moves Our Mission?

The key to building for the future is the organizational "who," the people who put our mission into action and power innovation. Staff retention is at an all-time high at NKF as more people understand the impact of kidney disease and commit to our mission. At the same time, we are bringing new ideas and perspectives on board to carry us forward and adapt our work to the current times.

In FY16 we welcomed exciting additions to our **Executive Staff** including, **Dolores Machuca-Ruiz, Senior Vice President of Marketing**, who will be keeping our messaging and branding contemporary and effective, while developing and maximizing our presence in new media. Previously, Dolores was Vice President of Diversity Communications at NBCUniversal, Inc. where she developed and implemented a company wide communications strategy for the company's diversity and inclusion initiatives. Her experience in this area promises to strengthen NKF's connection to expanding and changing demographics. Dolores was also Vice President of Communications

and Marketing for the American Cancer Society, a role whose areas of responsibility included social media, public relations, cause marketing, eRevenue, and eCommerce.

James Echikson, is NKF's new **Vice President, Corporate Development**. He brings significant corporate partnership experience from both for-profit and non-profit roles. This includes the American Society for the Prevention of Cruelty to Animals (ASPCA), where, as Senior Director, Corporate Partnerships, he expanded their base of support to new categories outside the pet industry, securing the most profitable partnership in the organization's history, with Subaru. As Vice President, Strategic Planning and Business Development for the National Football League, Jim successfully extended the league's footprint internationally with the launch of operations in Mexico. He is building relationships between NKF and nontraditional corporate supporters outside the healthcare/pharma industry, focusing on consumer products and services companies (e.g. supermarkets, food and beverage, retail, banks). He is overseeing



Lance Berman, MD, SVP and Chief Medical Officer at Relypsa receives the NKF Corporate Innovator Award from Kevin Longino, NKF CEO (center), and Jeffrey S. Berns, MD, NKF President (right).

all outreach, as well as maintaining current relationships, to support NKF's national and field-based activities.

As NKF's new **Medical Project Director, David Feldman, PhD**, is one of the people making CKD*intercept* really happen. David comes from a distinguished background in the private sector, having spent more than 25 years at Novartis Pharmaceuticals as a senior research scientist, specializing in cardiovascular and metabolic research projects. As an internationally recognized scientist in renin inhibition, David has made several contributions to the field of nephrology. While serving as the research lead on the global team that brought the first renin inhibitor to patients, David's laboratory generated and published the pre-clinical effects of this drug on the kidney. He also conceived and managed an international pre-clinical research program with studies executed by 30 scientists in various countries. He was also a lead contributor to various renal disease and hypertension projects and co-led two global teams to identify novel antithrombotic agents, one of which has been submitted to the FDA for testing in

humans. In addition to membership in the International Society of Nephrology and several other committees and professional societies, he has been published in numerous nephrology-related journals, and has presented and lectured at many seminars. David's passion for nephrology began while working for his PhD in Biology from SUNY at Binghamton. He was a Post-Doctoral Research Fellow at the Cleveland Clinic Foundation. He is currently working on the CKD*intercept* Summit of major public and private healthcare stakeholders and processing the data from this event, which will, in effect, drive the program in the future. David is proving that putting experience in the private sector to work in the non-profit arena is an effective way to fight kidney disease.

Support for NKF is, **investing in lives and the people who enrich those lives**. The dividends are a healthier patient population, less strain on national healthcare resources, improved quality of life for caregivers and families—and simply saving and improving many lives.



DR. PAUL OLSON

Nephrologist

Local Board Member, Dr. Paul Olson, Nephrologist, Ridgeview Clinics, Minneapolis, MN

After three decades of involvement with NKF, Dr. Paul Olson is still one of the Foundation's most active volunteers. Dr. Olson, a board-certified internist and nephrologist at Ridgeview Clinics in Minnesota became involved with NKF the moment he finished his fellowship in 1986 and hasn't stopped since. From local galas and NKF Golf outings, to the national Medical Advisory Board, to serving as chair of the local board, Dr. Olson has done it all. He even led the Minneapolis office during a time of transition from Affiliate to the national Headquarters! Some of Dr. Olson's favorite volunteer experiences have been with the KEEP Healthy program. "Doing the KEEP Healthy program is so satisfying. The real way we can cure kidney disease is with preventative measures." But Dr. Olson also counts our local fundraising events as

some of his most memorable. "Planning for the Great Chef's event is as satisfying as raising funds and eating great food. I love the golf tournament as well and always enjoy participating in the planning. There's fun stuff, and things that make a difference." There's no shortage of things NKF can point to when it comes to how Dr. Olson has made a difference in the lives of all people affected by kidney disease. One of his newest efforts has been as a supporter of the NKF Pro-to-Go program, which provides undeclared medical residents an opportunity to attend the annual NKF Spring Clinical Meetings. Considered the premiere nephrology conference in the country, SCM offers distinct course tracks for all healthcare professionals in the field of nephrology.

"The NKF Spring Clinical Meetings are great—I've always loved them. It's exactly the type of event that will get a resident interested in nephrology," says Dr. Olson. "Residents don't realize how much work goes into being a nephrologist and how valuable it is as a role. Nephrology is not just about kidneys, it's about the entire body. Residents need to know that. We're depended on for so much. And we're losing more nephrologists than we're gaining," he adds. NKF's Pro-to-Go program seeks to address the growing problem of diminishing numbers of professionals in the nephrology field by providing scholarships to promising clinicians and professionals that will allow them access to critical training and development.

An ardent supporter of the program Dr. Olson says, "The Pro-to-Go program makes medicine better. It's that simple. We need nephrologists in the field." Encouraging fellow board members, and all volunteers, to be involved with NKF through NKF Golf, galas and special events or sponsoring a Pro-to-Go resident, are just some of the ways Dr. Olson helps move the mission of NKF forward. "There is no doubt that when we come together, we can get a lot done as an organization. Programs like KEEP Healthy unify us. New programs like Pro-to-Go continue this tradition and mission of NKF."

What Our Work Really Means for People.

Imagine a healthier world. Kidney disease is about the impact it has on people's lives—their quality and length of life, their families, their finances, their options and opportunities. We measure progress in day-to-day gains for people living with this condition, and in what their lives can be in the future.

Imagine a world where kidney disease is caught “before early” and treated before it causes significant damage. Imagine a world where people don't have to go to a dialysis center three or four times a week to stay alive. Imagine a world where \$100 billion a year in public funding does not have to be diverted to kidney healthcare. Imagine a world with no wait list for people seeking a kidney. Imagine a world where people live healthier lives.

This is not a vision, but realities within our grasp.

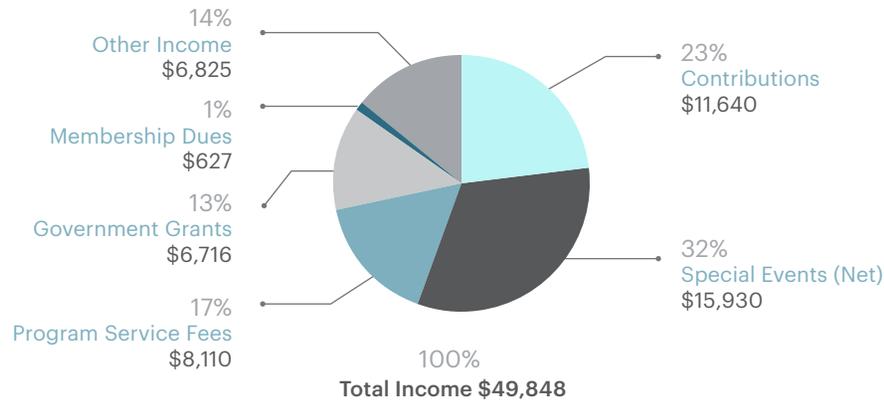
Now, imagine a world where kidney disease has become a rare thing, or even nonexistent, and you have The Vision.

PEOPLE FIRST

Financials

Figures depict the combined financial activities of the National Kidney Foundation and its Affiliates for Fiscal Year 2016.

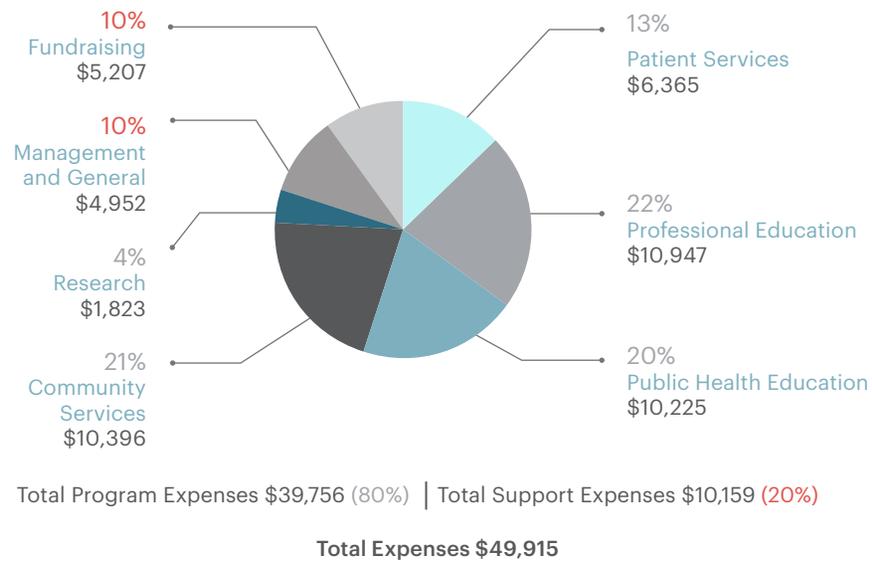
Public Support and Revenue (in thousands)



Assets (in thousands)

Cash and Cash Equivalents	\$8,396
Investments	\$20,123
Accounts Receivable	\$7,839
Inventories of Educational and Campaign Material	\$136
Prepaid Expenses	\$1,169
Property, Plant and Equipment (net)	\$2,851
Other Assets	\$158
Total Assets	\$40,672

Expenses (in thousands)



Liabilities and Net Assets (in thousands)

Liabilities	
Loans Payable	\$226
Accounts Payable and Accrued Expenses	\$5,270
Deferred Income	\$6,343
Other Liabilities	\$82
Total Liabilities	\$11,921
Net Assets	
Unrestricted	\$18,165
Temporarily Restricted	\$7,791
Permanently Restricted	\$2,795
Total Net Assets	\$28,751
Total Liabilities and Net Assets	\$40,672

Figures exclude financial information from NKF of Arizona and NKF of Central New York

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Director of the Cleveland Clinic Minority
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Cleveland Clinic Main Campus

Jummy Olanbani

Anchor/Reporter
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“As an NKF Board member, my specific goals include vertical integration of discrete, yet relevant, NKF constituencies. A need exists to effectively coordinate efforts, among and between, healthcare professionals, patients, providers, caregivers, insurers and governmental agencies.”
Joseph Cosgrove

“I’ve been a champion of NKF’s local initiatives for many years. I first became involved with the Foundation’s Pittsburgh chapter nearly 30 years ago when my son was diagnosed with a condition that damaged his kidneys. I am proud to share that I became a living donor 20 years ago when I donated one of my kidneys to him, and I am eager to support the Foundation’s efforts on a national scale.”
Brennan Hart

“Unfortunately, the number of people who are developing advanced kidney disease and in need of a kidney transplant is exploding. We, as healthcare providers, must therefore promote prevention and early detection of kidney disease.”
Charles Modlin

“I didn’t know that anything was wrong with my kidneys until they failed and I needed a transplant. Fortunately, my brother was a match and donated one of his kidneys to me nearly 20 years ago. We’re both thriving and I’m determined to spread the word about kidney disease so that others can catch kidney disease early.”
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“I feel very honored to be selected to serve on the Board of the National Kidney Foundation, having spent nearly three decades working with the organization on a variety of initiatives at both the national and local level.”
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Host Hotels and Resorts, L.P.	McCormick & Company, Inc.	Niche Media Holdings, LLC	Signal Energy Constructors
Hulu	MediaLink	NxStage	SSM Health Saint Louis University Hospital
ICF Consulting Group	MediaVest Worldwide	Others First	Standford Health Care
Indiana University Health	MEDITECH	PA Apt. Association East	Stifel, Nicolaus and Company, Inc.
Infiniti Abstracts, LLC	MedStar Health	Paul Hastings LLP	Stone Point Capital
INVNT	Meltzer Group, Inc.	Permian Transport and Trading	Stonebridge Companies
Ion Media Networks	Merck Sharp and Dohme Corp.	PhRMA	Stradley Ronon Stevens and Young, LLP
IPG Interpublic Group	Mesirow Financial	Pittsburgh Life Sciences Greenhouse	SurgiCare of Manhattan
K&L Gates	Mid America Transplant Services Foundation	Pittsburgh Pirates	Sutter Health CPMC
Kaiser Permanente	Mid-Atlantic Nephrology Assoc.	PNC Business	Teredesai, McCann, and Associates

The Bank of New York Mellon
Therma, Inc.
Thomas Jefferson University Hospital
Tocqueville Asset Management L.P.
Transamerica
Tristar Management
Turner Broadcasting Systems
UC Health
UHS of Delaware
Union Bank of California
United Way of Metropolitan Chicago

UnitedHealth Group
University of Chicago Medicine
University of Colorado Health
University of Illinois Health
University of Maryland Medical Center
University of Minnesota Medical Center,
Fairview Donor Transplant Program
University of New Mexico, Health
Sciences Center
University of Pittsburgh Medical Center
UPTV

US Renal Care
UW Health
VCU Health System
Viacom Media Networks
Wells Fargo
Wilmington Trust
Winston and Strawn LLP
Zelle Hofmann Voebel and Mason LLP
Zenith

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.

Estates and Trusts

Estate of Joseph M. Alberstadt
Estate of Elias J. Barakat
Anna M. Bell Trust
Estate of Jack Berroteran
Estate of Arthur Bourgoin
Clark W. Boyer, Sr., Irrevocable Trust
Tua Burkart Residual Trust
Estate of Timothy J. Calvin
Chi-San Chu Trust
Estate of Ingrid D. Climis
Estate of Edward F. Debard
Deinhart Joint Revocable Trust

Susan Lynn Denis Revocable Trust
Thomas D. Dobson Irrevocable Trust
Estate of Catherine Ferrarese
Estate of Charles Fjeld
Estate of David Jerome Foley
Estate of Gregory Jerome Goldring
Estate of Harriet Goldstein
Estate of Pauline Dianne Gotay
JAL JR Revocable Trust
Charles R. Jensen and Dorothy V. Jensen Revocable Trust
Estate of Mary J. Kester

Trust of Koyo M. Konishi
George H. Langenfelder Memorial Charitable Trust
Estate of Larry M. Lawson
Sandra K. McAninch Living Trust
Louis M. Mufich Trust
Estate of Josephine J. Musico
Milton N. Niggemeyer Estate
Nolan Revocable Trust
Estate of Camille Owen
Estate of Virginia B. Parham
Mary Camp Parks Family Living Trust

George E. Ramskill Testamentary Trust
Charles J. Ropke / Ann M. Ropke Revocable Living Trust
Estate of Lee M. Russell
Vernon L. Sachs Trust
Sandhoffer Living Trust
Estate of Mary Lou Schirmer
Estate of Francine Segall
South Dallas Trust
Estate of Joyce D. Specter
Charlotte M. Vollrath Revocable Living Trust
Sandra Vrono Living Trust

Foundations

American Renal Patient Care Foundation
Asofsky Family Foundation
Community Foundation of Anne Arundel County
The Barnard Charitable Fund
The BGR Foundation, Inc
Blum-Kovler Foundation
CBRE CB Richard Ellis Inc. Foundation
The Charles T. Bauer Foundation
The Charles McCutchen Foundation
William Cortelyou Donor-Advised Fund
John and Maurine Cox Foundation
Dart Group II Foundation Inc.
Exelon Foundation

Fair Oaks Foundation
FMU Charitable Foundation, Inc.
Greater Saint Louis Community Foundation
Stephen A. and Diana L. Goldberg Foundation, Inc.
The John and Marcia Goldman Foundation
W. R. Grace Foundation, Inc
Hospira Foundation
Independent Dialysis Foundation
Issa Family Foundation
Gene and Jerry Jones Family Foundation
JSJ Family Foundation
Kidney Foundation of California
The Living Legacy Foundation

Mangione Family Foundation
McDowell Longino Charitable Fund
Mid America Transplant Services Foundation
John Moffitt Foundation
Harvey E. Najim Family Foundation
The Nokomis Fund
The Oregon Community Foundation
J and K Pi Family Foundation, Inc.
The Pittsburgh Foundation
Research Foundation of SUNY
Richman Private Family Trust Foundation
Marian Renee and Edward Saltzberg Foundation
The Sandra Atlas Bass and Edythe and

Sol G. Atlas Fund
Semmes Bowen and Semmes Foundation, Inc.
Silicon Valley Community Foundation
Simms Family Fund
SunTrust Foundation
Wasserman Foundation
Harry and Jeanette Weinberg Foundation, Inc.
Wells Fargo Foundation
Wentcher Foundation
The Woods Charitable Foundation
Youth That Care Inc.



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