

National  
Kidney  
Foundation™



# Strategic Plan $\frac{2013}{2018}$

Awareness • Prevention • Treatment



Over the past two decades, the face of kidney disease has been rapidly evolving. Landmark developments in nephrology have catalyzed new approaches to treatment, and groundbreaking information regarding prevention has altered the world's understanding of the disease.

**T**he National Kidney Foundation is proud to be considered a thought leader in the field of kidney disease, and we aim to share our knowledge so that everyone – the general public, patients, medical professionals, public officials, etc. – has accurate information about the kidney, and an appropriate sense of understanding and urgency around kidney disease. Our goal in communicating this information to our diverse audiences is to ensure that those at risk are aware of the kidney's role in their health and of what kidney disease is, that

practitioners have the necessary information and training to prevent its progression when possible, and that those living with kidney disease receive the right treatment.

We carry out this work at a national level from our corporate headquarters in New York City, as well as through local divisions and affiliate organizations throughout the country. This structure enables us to drive national dialogue around kidney health while simultaneously providing opportunities for individuals to access our resources and support our work in their own communities.

**This strategic plan will drive the National Kidney Foundation's work for the coming five years.**



We will leverage our knowledge and experience to promote the three underlying pillars of the organization's strategic direction: the **Awareness, Prevention, and Treatment** of kidney disease. Our energy will be wholly directed toward enhancing the lives of all individuals who experience, are at risk for, or are affected by kidney disease. We hope that you will join us in advancing this work.

## HISTORY OF THE NATIONAL KIDNEY FOUNDATION

# 1950-1997

**T**he National Kidney Foundation was established in 1950 by Ada DeBold in an effort to save the life of her young son.

As a small child, Bobby had been diagnosed with pediatric nephrosis, a disease that causes the kidney to lose protein and the body to swell with water. At the time, this debilitating illness had a 90 percent mortality rate. In a heroic effort to find a cure, Ada brought together a group of clinicians and researchers from around the United States to share their findings and develop new approaches to understanding and treating the disease.

Bobby passed away from nephrosis at the age of four; however, the work that Ada set in motion eventually led to a successful treatment and catalyzed a lifesaving national movement.

Beginning with Ada's pioneering efforts to raise awareness, encourage research, and provide treatment, the National Kidney Foundation continued to help victims of kidney disease and their families, and to raise money to fund research.

With new technological developments in the 1960s, it became possible to treat kidney failure through dialysis. This meant that kidney disease was no longer inevitably fatal, but rather a chronic illness with the potential for treatment and management. As the field of kidney disease treatment shifted, the National Kidney Foundation honed our focus to providing treatment for end-stage patients experiencing kidney failure, while also awarding significant fellowships to support ongoing research.

In the 1970s and 1980s, we increased our commitment to research funding, while also raising awareness of the importance of organ donation. The National Kidney Foundation launched *The American Journal of Kidney Diseases*, which is now considered to be a leading peer-reviewed medical journal for cutting-edge clinical nephrology. We recognized the need to advocate for federal support of kidney disease patients, providers, and research. From that point on, the National Kidney Foundation's leadership has been instrumental in securing legislation and funding for both treatment and research.

Since 1968, the National Kidney Foundation has provided more than **\$100 million** in research grants to the field.



On November 15, 1950, Ada DeBold, and her husband Harry, called the first meeting of the Committee for Nephrosis Research.

During this period, we also focused on developing programs to serve kidney patients and their families, targeting the 600,000 individuals diagnosed with kidney failure. We continue to offer a broad range of programs to reach those in need.

## CHANGING THE FACE OF KIDNEY DISEASE

# 1997-2013

**T**he National Kidney Foundation strives to use what we learn through our own research, as well as from relevant external data, to adjust our approach and develop new programs. We continually work to identify new information that will advance the field and ensure better outcomes for those impacted by kidney disease.

In 1997 the National Kidney Foundation published a set of cutting-edge clinical practice guidelines for the care of dialysis patients. Since that time, our Kidney Disease Outcomes Quality Initiative (KDOQI) has produced a total of twelve original guidelines, including the groundbreaking *Clinical Practice Guidelines for Chronic Kidney Disease: Evaluation, Classification and Stratification* in 2002. These evidence-based guidelines have dramatically changed the approach to and quality of care for kidney patients worldwide.

*“The publication of the 2002 KDOQI Chronic Kidney Disease guideline, with its standardized terminology and eGFR-based staging system, was the most important thing that’s happened in dealing with CKD patients since I entered the field.”*

- Nathan Levin, MD

The 1997 guidelines had a significant and measurable impact on the care and outcomes of hundreds of thousands of dialysis patients. Subsequent guidelines, encompassing the entire spectrum of kidney disease, now have the potential to improve care for millions more. These pivotal findings have, over time, directly influenced the necessary direction of the National Kidney Foundation.

### Key Clinical Findings:

- 73 million American adults – one in three – are currently at risk for kidney disease, because they have diabetes, hypertension, or a family history of kidney disease.
- 26 million Americans currently have chronic kidney disease (CKD).
- Minorities, including African Americans, Hispanics, Pacific Islanders, and Native Americans, as well as seniors are at increased risk for kidney disease.
- Kidney disease progresses through five stages; this classification system is the standard by which patients are diagnosed and treated today.
- Kidney disease can be detected through simple tests.
- The onset of early-stage kidney disease and the progression from early to late stage illness are often preventable with appropriate testing, treatment, and risk factor management.



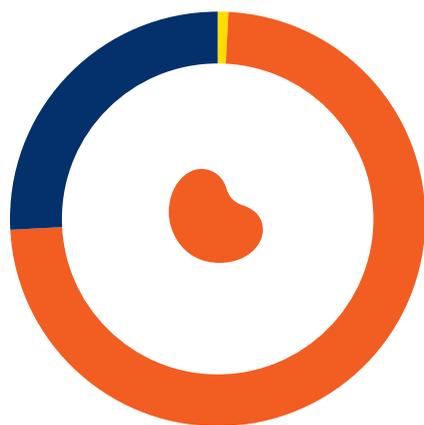
**Kidney Disease kills more people every year than breast cancer, prostate cancer, or leukemia.**

# CHANGING THE FACE OF KIDNEY DISEASE 1997-2013

(continued)

## What These Findings Have Meant for Our Work:

Before the clinical practice guidelines were developed, both the field of kidney medicine and the National Kidney Foundation focused primarily on the 600,000 patients with treated kidney failure. Neither researchers nor practitioners were aware that kidney disease could be identified in earlier stages. Furthermore, the field had not fully recognized the scope of individuals impacted by kidney disease beyond those who would experience organ failure.



Individuals At-Risk:

**73 million**

Individuals with CKD:

**26 million**

Individuals with Kidney Failure:

**600,000**

In light of the clinical practice guidelines, we learned that early-stage kidney disease is not only identifiable, but that it can often be prevented from occurring in at-risk individuals, and from progressing in those experiencing the first stages of kidney damage. What this information meant to practitioners, consumers, family members, and our organization was a watershed realization:

Having kidney disease does NOT mean you have to die.

It became our organizational imperative to tell this story, and to use this information in continuing to advance kidney health. Given this new early detection ability, the scope of the National Kidney Foundation's efforts necessarily broadened: in addition to our traditional target audience of the 600,000 individuals with treated kidney failure, we were now aware of the 26 million Americans living with CKD, and the 73 million people at risk for kidney disease.

Rising to the opportunity presented by this new knowledge, the National Kidney Foundation focused during the 2000s on spreading the word within the field of nephrology about the new data released in the clinical practice guidelines, and the importance of implementation.

At that time, only five percent of individuals with early-stage kidney disease were being diagnosed.

Accordingly, we increased our efforts to motivate practitioners to begin to use staging, to demonstrate the significance of early diagnosis, and to strengthen our support of all individuals throughout the spectrum of kidney disease. Our landmark developments toward this end included the *Kidney Early Evaluation Program* (KEEP®). KEEP remains the most effective and comprehensive detection program for kidney disease nationwide, and is designed to identify kidney disease at the earliest stage possible.

**\$41 billion**

is spent every year -  
17% of the US Medicare  
budget - on people with  
kidney disease.

## OUR VISION FOR the Future

**A**s the National Kidney Foundation reached the milestone of 15 years since the initial clinical practice guidelines were published, we felt obligated to pause and reflect upon the history of our organization, the organic growth that we have experienced in response to the evolving face of kidney medicine, and the current state of both the field in which we work and the programs and services we provide. This analysis yielded a clear strategic direction for the next five years.

While we still work to secure the highest quality treatment for individuals experiencing all stages of kidney disease and promote research to advance kidney care, the knowledge that our field has gained over the past two decades has given us the opportunity and, in fact, the mandate to take the next step in elevating the Awareness, Prevention, and Treatment of kidney disease.

We now know that the number of individuals at risk for and directly affected by kidney disease is greater than we could have ever imagined in 1950 when we set out to help four-year-old Bobby DeBold find a cure for his nephrosis.

Moreover, we know that we have the knowledge, resources, and capacity to save millions of lives by identifying kidney disease early and helping people to manage their kidney health.

In order to achieve this impact, however, we **must** build awareness among the 73 million individuals at risk for kidney disease.

Preventing kidney disease keeps people healthy and saves precious health care resources – dialysis treatment for an average patient costs approximately  
**\$70,000 each year**

The general public must be aware of the life-sustaining role the kidney plays in their health, and of the risk factors and real danger presented by kidney disease. People with high blood pressure, diabetes, or a history of kidney disease must know that they are at high risk for kidney damage, as well as ethnic and racial minority groups and seniors.



## OUR VISION FOR the Future

(continued)



All of these individuals must be empowered to seek testing and to understand how to manage kidney disease risk factors. Only this awareness will enable those at risk to prevent the onset of early stage illness, and those with early kidney disease from experiencing organ failure. Physicians must also have the resources to detect kidney disease early and provide appropriate treatment and management to prevent disease progression.

### **This is our call to action.**

We are neither moving away from our traditional constituents nor changing direction with our

work, but we will actively and aggressively use the knowledge that we have gained over the past 60+ years to have a greater impact on the field of kidney health at both local and national levels. This plan represents the next logical step that the National Kidney Foundation is obligated to take as an organization to drive greater change and have greater impact on behalf of all individuals touched by or at risk for kidney disease.

We are and will continue to be the leading source of information and support for individuals and communities touched by kidney disease, and the National Kidney Foundation will focus our efforts on three core pillars.

### **PILLAR I Awareness** **PILLAR II Prevention** **PILLAR III Treatment**

We are proud to present an overview of the National Kidney Foundation's direction for the next five years, mapped out according to the strategic drivers and objectives that will enable us to reach our goals toward each of our three pillars. We will use these pillars to drive our programs and research, and we will measure our outcomes in each. This approach will ensure that we can provide clear leadership throughout our own network and the field, and it will allow us to report on our successes and challenges.

**Join us as we embark on this exciting next phase of work.**



# Core Pillars

Awareness • Prevention • Treatment



## PILLAR I

# Awareness

### Kidney Disease Awareness Today:

The general public, and in many cases those at risk, are not aware of the kidney's role in keeping the body healthy or the dangers of kidney disease. Even those that are directly affected by kidney disease are not aware of its severity.

### Strategic Drivers and Objectives:

#### 1. Create broad awareness among the general public.

We will use *Now! You Know*, our national multimedia awareness campaign to:

- Increase the general public's knowledge of the kidney and its life-sustaining role in keeping the body healthy.
- Increase the general public's knowledge of kidney disease by raising awareness of risk factors, demographics at high-risk, general management of risk factors, and the scale of impact (73 million individuals at risk).
- Target specific awareness-building and educational efforts toward high-risk audiences (e.g. minorities, the economically disadvantaged, the elderly).
- Increase the general public's knowledge that kidney disease is preventable.
- Our *World Kidney Day* celebration will leverage messages of *Now! You Know*, and generate additional awareness across the country and world.



#### 2. Provide basic education to at-risk individuals.

We will use *Your Kidneys and You* to reach at-risk individuals directly. We will conduct presentations and distribute materials that raise awareness about the kidney and kidney disease in a way that is easily understandable and actionable.

#### 3. Provide screening to at-risk individuals.

We will use community-based risk assessment activities to increase awareness of risk factors and to conduct individual kidney health screenings.

#### 4. Raise the general public's awareness of the National Kidney Foundation as the leading source for this information.

### Awareness in Five Years:

Kidney disease occupies the center stage in the public consciousness, so that an appropriate sense of urgency exists around the disease.

The National Kidney Foundation provides a comprehensive continuum of education that reaches all at-risk and affected individuals with awareness and messages that are appropriate to their level of knowledge and/or illness. Individuals are able to utilize this spectrum of educational tools and services to access the information they need, whether it be basic awareness or specialized clinical data and treatment resources.

As a result, those at-risk understand the importance of controlling risk factors such as high blood pressure and diabetes, and also understand the kidney's life-sustaining role in the body and why lifestyle measures that protect kidney health are critical. Those with a diagnosis understand what it takes to prevent the disease from getting worse.

In sum, the general public, at-risk individuals, patients, and their families are aware of what kidney disease risk factors are, how to manage those factors, who is at highest risk, and who to turn to for resources and information.



## PILLAR II

# Prevention

### Kidney Disease Prevention Today:

Early stage kidney disease is not being identified and diagnosed as early and often as is necessary. Patients are frequently told not to worry until kidney damage has progressed to near failure. Furthermore, patients do not have the necessary education or resources to manage their own risk factors and lifestyle to prevent initial kidney damage and progression of the disease.

### Strategic Drivers and Objectives:

#### 1. Empower at-risk individuals to seek testing and treatment.

Through ongoing community-based and online virtual screening activities the National Kidney Foundation will:

- Empower at-risk individuals to ask clinicians for kidney disease testing/treatment.
- Provide information and tools to help the public assess their risk for kidney disease and seek testing.

#### 2. Educate at-risk and early-stage patients around prevention of kidney disease progression.

Through our online [National Kidney Foundation Wellness Center](#), we will provide additional resources to at-risk individuals, patients, families, and the general public regarding the kidney, kidney disease, lifestyle, nutrition, and the program resources available through the National Kidney Foundation.

#### 3. Facilitate continuing education for primary care practitioners regarding the identification, diagnosis, and care of early-stage patients.

- We will provide education specific to primary care practitioners, including both Continuing Medical Education (CME) and non-accredited programs.
- We will use our [Primary Care Focus](#) programs to convene key opinion leaders, address systemic obstacles for CKD diagnosis, and facilitate integration of clinical practice guidelines and staging into local and national health systems, as well as individual physician practices.
- We will partner with medical associations and societies to educate member constituents regarding the [Joint Position Statements on 2012 Guidelines](#), to facilitate adoption and implementation of current clinical practice guidelines. These guidelines will drive prevention efforts nationwide.
- We will engage with research groups, including the [CKD Prognosis Consortium](#), to gather and originate new data, and will provide grant funds to support external research around identification, diagnosis, and early-stage patient care.
- To provide a comprehensive syllabus of materials for practitioners and enable the practical implementation of the

### Prevention in Five Years:

The National Kidney Foundation will reach those at risk before kidney disease occurs, and impact those in earliest stages so that progression to later-stage disease is no longer inevitable. At-risk individuals will have the educational tools to maintain a healthy lifestyle that protects kidney health, and will be empowered to seek out testing and treatment from their physicians.



Primary care practitioners will know which tests to order and how to recognize early-stage kidney disease, which will increase the total number of diagnoses of kidney disease. In addition, primary care practitioners have the knowledge and tools to treat early-stage kidney disease in order to slow its progression, and refer their patients to nephrologists when they need more specialized care.

Kidney disease training will be integrated into health systems and individual physician practices, and practitioners will have robust patient education and metric collection tools with which their outcomes may be measured.

latest guidelines and clinical science into patient care, we will continue to grow our inventory of educational resources.



## PILLAR III

# Treatment

### Kidney Disease Treatment Today:

The National Kidney Foundation offers a multitude of professional education programs, a major annual medical conference, four peer-reviewed journals, and multiple clinical practice guidelines to help practitioners stage and treat kidney disease and related complications. Both the patient and professional education programs are well recognized and well used, but their impact on patient outcomes has not been measured. Approximately 17,000 kidney transplants are performed annually, yet the American waiting list for life-saving kidney transplants includes 95,000 individuals. Many people are unaware of living donation as an option, including patients already on dialysis. Additionally, extensive barriers exist for potential living donors, including the necessity to take unpaid leave, the need to incur out-of-pocket expenses when travelling to donate a kidney, and lack of follow up.

### Strategic Drivers and Objectives:

#### 1. Gather and publish original epidemiologic data and analyses, and provide grant support for promising research.

- Through the [CKD Prognosis Consortium](#), we will continue to support large-scale epidemiologic research regarding CKD risk factors, progression and prognosis. In doing so, we will gain insight in how to improve quality of life for those with kidney disease and learn more about kidney disease causes and progression, and how it can be slowed or even reversed.
- We will continue to publish research in the National Kidney Foundation's peer-reviewed medical journals, including [American Journal of Kidney Diseases](#), [Advances in Chronic Kidney Disease](#), [Journal of Renal Nutrition](#), and [Journal of Nephrology Social Work](#), as well as in constituent publications.

- We will renew our funding of research of promising scientists (e.g. Young Investigator Grants and Nephrology Fellowships).

#### 2. Improve outcomes through patient and professional education.

- We will continue to build our robust inventory of creative and practical educational resources for kidney disease patients and health care professionals.
- Through our [Spring Clinical Meetings](#), we will provide a forum for kidney professionals (e.g. nephrologists, fellows and residents, advanced practitioners, pharmacists, nurses, social workers, clinical dietitians, etc.) to access comprehensive Continuing Medical Education (CME) and other training resources, as well as professional networking opportunities.

- We will facilitate the adoption and implementation of updated [Clinical Practice Guidelines](#) by developing targeted education materials for patients and health care professionals.
- To further promote the newly refined staging and classification of chronic kidney disease, we will collaborate with a broad range of organizations, including other voluntary health organizations, academic institutions, health systems, and managed care organizations.

#### 3. Increase access to kidney transplantation for those with advanced kidney disease.

- We will increase awareness around living donation as an option through many education vehicles and communication platforms.
- We will reduce barriers for potential living donors by continuing our legislative advocacy efforts and patient education programs, including those mentioned above.
- We will increase both the number of organs available for transplantation and the number of transplants performed annually, thereby reducing the national waiting list.

#### 4. Continue to support patients, caregivers, and organ donors.

- We will maintain the National Kidney Foundation's patient hotline, [National Kidney Foundation Cares](#), which offers support for individuals affected by kidney disease, organ donation, or transplantation.



## PILLAR III Treatment (continued)

- Through the **PEERS Program**, the National Kidney Foundation's telephone-based patient-to-patient peer support program, we will continue help patients adjust to chronic kidney disease, dialysis, and transplantation.

### 5. Advocate on a national level on behalf of current and potential kidney disease patients.

Through our ongoing legislative advocacy efforts and public policy agenda we will:

- Secure annual appropriations through Congress to fund the CDC's chronic kidney disease program.
- Lobby the House of Representatives and Senate to extend Medicare coverage for transplant recipients, and to create new Medicare benefits to support kidney disease patients.
- Continue to work with the Congressional Kidney Caucus to identify issues, needs, and opportunities for public policy.
- Build and implement systems that will enable kidney advocates to contact their elected officials more efficiently and effectively.

### 6. Measure outcomes and impact.

We will conduct regular surveys of the patients and health care providers using our educational programs and implements deeper outcomes measures for all programs.

### Kidney Disease Treatment in Five Years:

The National Kidney Foundation conducts regular surveys of the patients and health care providers using our educational programs and implements reliable outcomes measures for all CME programs, enabling us to assess our impact on primary care practice, nephrology practice, and patient outcomes.

Research continues to be published in leading peer-reviewed journals, which will lead to improvements in health and quality of life for individuals with kidney disease and enable researchers and practitioners to learn more about causes and prevention of progression. Ongoing patient and professional education enable the practical implementation of guidelines and the latest clinical science into patient care, improving patient outcomes through education.

An additional 10,000 transplants are performed annually, and the waiting list for kidneys is therefore drastically reduced. Barriers to donation have been reduced so that everyone who wants to donate is able to do so. The National Kidney Foundation addresses the needs of the kidney and transplant communities with a robust public policy agenda, which include coverage for kidney disease under Medicare and Medicaid, organ donation programs supported by HRSA, and medical research sponsored by the NIH. The National Kidney Foundation works with Congress and other federal agencies to pass legislation and develop rules to implement kidney programs that result from new laws.

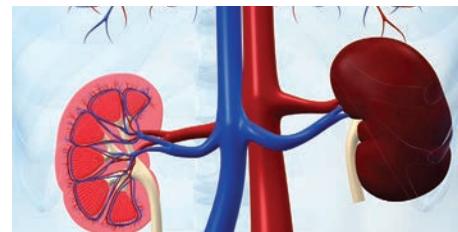


Health care needs and the health care delivery system have changed significantly over the five year plan period. The National Kidney Foundation partners with large employers and health insurers to establish system-based solutions that facilitate timely diagnosis and management, leading to a reduction in the clinical and economic burdens currently associated with Chronic Kidney Disease. The National Kidney Foundation's advocacy work continues to focus on adequate Medicare coverage for our patients, ensuring improved access to and quality of care for all.

Over the coming five years, the National Kidney Foundation will focus on creating a continuum of services and programs that promote kidney health. Our model will focus on Awareness, Prevention, and Treatment that reaches all at-risk and affected individuals.

**O**ur goal is to ensure that the National Kidney Foundation's resources are easily available to all those who need them. **We will create** an appropriate sense of urgency around kidney health by raising awareness among the 73 million individuals that are at risk for kidney disease. Kidney disease should occupy center stage in the public consciousness so that all are aware of the risk factors, how to manage those factors, who is at highest risk, and who they can turn to for resources and

information. **We will reach** those at risk before kidney disease occurs, and impact those in earliest stages so that the progression to kidney failure is no longer inevitable. We will help people to understand the risk factors associated with kidney disease, and to learn how to manage them. **We will ensure** that practitioners are equipped with latest screening and management information, so that they know which tests to use, how to recognize early stage patients, and how to treat early stage disease. **We will promote** awareness regarding the importance of finding kidney disease early and initiating treatment to slow progression.



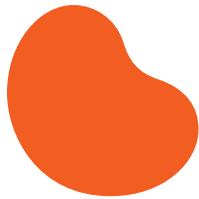
## Join us

in supporting this strategic direction – promoting our three pillars for kidney health:

**PILLAR I** Awareness  
**PILLAR II** Prevention  
**PILLAR III** Treatment

Our impact will be strengthened by the power of your support.





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Kidney  
Foundation™

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