

Proposal requesting support for the

**National Kidney Foundation of Northern California's  
Chronic Kidney Disease Education Program**

**Summary**

The proposed Chronic Kidney Disease (CKD) Education Program would serve individuals newly diagnosed with all stages of chronic kidney disease: from stage 1, which indicates normal kidney function, but with early signs of kidney damage, to stage 5, indicating severe kidney failure generally requiring dialysis or kidney transplantation. The program would provide patients at each stage of CKD with information specific to their condition, educational materials, counseling, recommended steps for slowing the disease's progression and information about available treatment options. The CKD Education Program would provide one-on-one counseling sessions and group seminars featuring medical and social service professionals both at the NKF of NC's headquarters in San Francisco and in health centers in the North, South, and East Bay on a rotating basis. In addition to these one-on-one and group counseling sessions, the program would maintain follow-up contact with both patients and their referring physicians. The CKD Education Program would be coordinated through the San Francisco headquarters of the NKF of NC by a full-time health educator/administrator and a part-time program assistant. Programming would take place both at NKF of NC's offices and in Bay Area health centers on a rotating basis, allowing patients to choose times and locations convenient to their schedules.

Studies have shown that patient education has an impact on the long-term health and survival of individuals with chronic kidney disease. But because of staff and funding shortages and poor coordination between doctors, healthcare providers, social service workers and educators, few educational programs like the CKD Education Program currently exist in Northern California. The NKF of NC is striving to feel this vital need by implementing an initial CKD Education Program in the San Francisco Bay Area. The budget for implementing the program is approximately \$125,000 dollars, which would support the hiring of one health educator/administrator to supervise the program, one administrative assistant, the development of program materials and web resources, and program costs for one year. Because of the demonstrable need for such programs in other areas, it is expected that, once established, the pilot CKD Education Program will be expanded into other medical centers throughout the Northern California region.

**The CKD Education Program Community Need and Opportunity for Impact**

According to the World Health Organization (WHO), chronic conditions like CKD will become the main cause of death and disability in the world over the next two decades. Currently, the prevalence of all chronic diseases is growing and challenging the capacity of governments to provide coordinated systems of care. In response, WHO has launched a project Innovative Care for Chronic Conditions that encourages programs like the

CKD Education Program, which attempt to improve local capacity for care and help coordinate currently fragmented health delivery systems.

Approximately 20 million people in the United States suffer from diseases of the kidney and urinary tract. Of this number and at a cost of 15 billion dollars each year more than 300,000 experience kidney failure and require dialysis or transplantation in order to live. Today, kidney disease is the ninth leading cause of death in the United States; one in nine Americans has some level of kidney damage. Contributing to these statistics are figures showing that racial minorities, particularly African Americans, are disproportionately affected by kidney disease. While African Americans comprise only 12 percent of the nation s total population, they account for 32 percent of patients with kidney disease in the United States. Factors contributing to kidney disease, such as diabetes and hypertension, are also disproportionately high among African Americans when compared to the incidence among Caucasians. Latinos and Asian Americans have also been shown to have disproportionately high rates of kidney disease when compared to the incidence and prevalence among Caucasians.

In Northern California, the incidence of kidney failure is highest in communities with large minority populations, such as Alameda County and areas of San Francisco and San Jose. The National Kidney Foundation of Northern California has responded to this need by concentrating a large portion of its preventative, educational and patient service programs in these areas. The CKD Education Program the next logical step in the NKF of NC s program development will provide education and counseling services to patients newly diagnosed with kidney disease, a group that is currently underserved and for whom the proposed program can have a significant effect on health and well-being.

Studies have shown that early education about the realities of kidney disease and its various treatment options can have a significant impact on the long-term health of patients. But at present, few medical centers have the available staff or resources to provide regular, comprehensive educational programs. In fact, uninsured patients diagnosed at San Francisco General Hospital, one of the few hospitals with an established program in place, receive counseling and education at a level much higher than most insured patients.

The effects of this health education gap are significant, impacting both the objective health of patients and their quality of life. Poorly prepared patients are less likely to be aware of treatment options such as peritoneal dialysis and home hemodialysis, which provide equally effective treatment while affording greater personal freedom than center-based dialysis therapy. These poorly equipped patients are also much less likely to utilize permanent arterial-venous fistulas which require early surgical placement for dialysis access and instead must utilize artificial grafts or catheters, which are considerably less durable and more prone to complications requiring hospitalization. In addition, late referral to a nephrologist, another common consequence of poor patient education, can significantly limit the management of co-morbidities such as hypertension, diabetes, malnutrition and anemia, conditions which not only contribute to kidney damage and thus

increased mortality rates, but also negatively impact patients' quality of life, as well as the economic cost of disease management.

The CKD Education Program aims to close the educational gap by providing educational programming to patients newly diagnosed with kidney disease, free of charge. The education program will include three separate components:

- **Individual Counseling and Education.** Patients, referred to the CKD Education Program by their primary care physicians, will receive initial one-on-one counseling with a trained health educator. These individual sessions will offer information, specific to each patient's needs and disease burden, on the realities of kidney disease and its treatments, will address patient concerns and questions in-depth, and provide take home resource materials for patients and their families.
- **Group Seminars.** In addition to individual sessions, the CKD Education Program will offer group seminars for patients and their family members. These half-day seminars will provide patients with broader educational presentations about disease management, lifestyle changes that can help slow disease progress, dialysis, transplantation and other treatment options. Group seminars will also include presentations by doctors, dialysis nurses, social workers, and dieticians, serving to introduce patients to the professional resources available to them as they manage their disease.
- **Follow-Up.** The goal of the CKD Education Program is to ensure that individuals with chronic kidney disease are provided with access to resources both at the time of initial diagnosis and as they continue to manage their disease. The program will offer follow-up counseling, referrals, as well as on-going staff, physician and patient evaluations of program effectiveness.

Individual counseling sessions, group seminars, and follow-up will be coordinated through the NKF of NC's San Francisco headquarters and will take place both at the NKF of NC's offices and at local health centers throughout the North, South, and East Bay Areas. By offering programs at several rotating locations in the Bay Area, the CKD Education Program aims for flexibility, allowing patients to participate in programs convenient to their schedule.

While the primary objective of the CKD Education Program is to improve the health and well-being of patients diagnosed with kidney disease, the program will also positively impact the considerable financial burden disease management places on the healthcare system. At present, patients with advanced CKD (stages 4-5) make up only 0.6% of the Medicare population, but account for approximately 6% of Medicare expenditures. The average annual cost of dialysis is approximately \$65,000 per person; transplantation costs include approximately \$90,000 for transplant surgery and \$15,000 or more per year for medications required for the remainder of the recipient's life. The CKD Education Program encourages behaviors such as dietary responsibility, regular medical visits, and utilization of available resources, which can slow disease progression and delay or even prevent the need for these costly treatments. In areas such as Alameda County where approximately thirty percent of all residents earn less than the state median income and a

high number of citizens are uninsured, the preventative aspects of the CKD clinic program can significantly lessen the personal financial burden of disease management.

### **Program Evaluation**

Outcome tracking and evaluation are important components of the CKD Education Program. Both the on-site health educator/administrator and administrative assistant would collect outcome data through patient evaluation, physician feedback and through the participating medical center's data collection system. Measurable goals for the CKD Education Program would include the following:

- For patients with advanced CKD (stages 4-5): increased preparedness for dialysis or transplantation, including increased early transplant rates, utilization of home therapies such as peritoneal dialysis or home hemodialysis, increased prevalence of arterial venous fistula vs. temporary grafts for dialysis access, and reduced hospitalization, emergency room utilization and dialysis catheter utilization rates. The program would also educate patients about the proper treatment of anemia, renal osteodystrophy, and hypertension. The NKF of NC will work with the Transpacific Renal Network to track treatment modality choices and other variables among patients. The first year program goal would be to increase the rate of home therapy utilization in Alameda County, as well as increase the rate of arterial-venous fistula utilization among hemodialysis patients.
- For patients with moderately advanced CKD (stages 2-3): increased education about the proper treatments to slow the progression of CKD and delay or prevent the need for costly therapies such as dialysis and transplantation.
- For patients with stage 1 CKD or no CKD, but at-risk: increased education about the early interventions to prevent CKD, increased screening for at-risk patients, and improved partnerships with medical providers to educate and empower patients.

Evaluation of program effectiveness would be on-going. It is expected that regular reports tracking the above measurable criteria would also be generated for both internal and funder review.

### **Budget**

The cost of implementing the CKD Education Program in the San Francisco Bay Area will be approximately \$125,000. This cost reflects both the development phase of the program, including hiring of one full-time health educator/administrator and one part-time administrative assistant to direct and manage the program, program planning and staff training, development of program materials, website resource development, and program marketing and outreach to healthcare professionals and providers; and the costs of one year of patient programming in the Bay Area, including administrative and consultant fees, brochures and materials for distribution, seminar costs and miscellaneous expenses. While the largest portion of program expense is related to the development phase of the program, the staff and materials developed during this period will

significantly decrease the cost of replicating the program in other medical centers in the region.

## **Conclusion**

In the United States, cases of kidney failure requiring dialysis or transplantation are expected to double over the next decade and continue to increase as our population grows older. Currently, the US health system is ill equipped to manage this drastic increase in chronic disease effectively. Programs like the proposed CKD Education Program can provide an invaluable resource for patients, doctors and healthcare providers alike, by coordinating access to educational materials and resources and ensuring that every individual diagnosed with CKD is exposed to the full range of services and treatments available to them.

By initiating the program in the San Francisco Bay Area, the CKD Education Program will be serving the Northern California communities with the greatest need. But with kidney disease on the rise, there is a demonstrable need for a replicable, sustainable model that can be expanded throughout the Northern California region. A grant supporting the development and initial implementation of this program will help to ensure that as cases of chronic kidney disease increase in Northern California, the programs that can make a demonstrable difference in the health and well being of these patients will, in turn, expand to meet their needs.