

NKF Peers Mentoring Program:

An Overview and Lessons Learned

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The article provides an overview of the National Kidney Foundation's Peers mentoring program. Following a brief discussion of the evidence behind peer support across disease states, the article reviews data collected since the program's official launch in September 2011 through December 31, 2015. Potential challenges and lessons learned from the program to date are highlighted and discussed.

INTRODUCTION

Chronic kidney disease (CKD) is a growing public health concern, although much of the general public remain unaware of CKD and its risk factors. 1 in 3 American adults is currently at risk for developing kidney disease (Nwankwo, Yoon, Burt, & Gu, 2013). Additionally, more than 661,000 Americans have kidney failure. Of these, 468,000 individuals are on dialysis, and approximately 193,000 live with a functioning kidney transplant (USRDS, 2015). Eighty-nine percent of ESRD patients reported that the disease caused many changes in their lifestyles (Kaitelidou, Maniadaakis, Liaropoulos, Ziroyanis, Theodorou, & Siskou, 2005).

Peer support is reported to be effective in helping kidney patients adjust to kidney disease, long-term dialysis therapy (Hughes, Wood, Smith, 2009; Perry, Swartz, Brown, Smith, Kelly, & Swartz, 2005), and kidney transplantation (Faulk, 1999; Leshowitz, 1995). It also improves depression (Travis et al., 2010), social isolation, self-esteem, and self-management (Feroze, Martin, Reina-Patton, Kalantar-Zadeh, & Kopple, 2010; Symister & Friend, 2003). This, in turn, leads to better health outcomes and survival (Thong, Kaptein, Krediet, Boeschoten, & Dekker, 2007).

Peer support programs utilize someone who is living with the same disease to assist patients in managing their own health. This can be particularly effective when the patient is newly diagnosed or is having trouble coming to terms with the disease (Taylor, Gutteridge, Willis, & Carol, 2016).

In addition, peer support has become strongly linked with attempts to increase patients' ability to self-manage their condition, and the drive to improve healthcare outcomes (Heisler, 2006).

Peer support works because patients are able to give each other something the clinician does not have—shared life experience. It is valuable to be able to talk to someone who can listen and empathize to help gain confidence and a greater sense of control, and to have access to practical information based on the lived experience of treatment from the perspective of someone who has “been there” (Taylor et al., 2016).

People diagnosed with a new medical condition have the added pressure of feeling isolated, often not knowing anyone else in their social circle who has experience with the condition (House, 2001). Patients often seek knowledge, strength, and hope when the path ahead seems uncertain or scary. Research shows that people often cope better when they interact with peers with whom they identify and share common experiences. In this way, feelings are validated, social isolation and stigma are reduced, hope for the future and optimism grows, and experiences are normalized (Dunn, Steginga, Rosoman, & Millichap, 2003).

Additionally, quality time with healthcare professionals seems to be increasingly limited. Past surveys of dialysis facilities found that 15%–36% of patients on hemodialysis were seen by a physician or advanced practitioner at least one time per week, whereas 21% of patients were seen monthly or less (Erickson, Tan, Winkelmayr, Chertow, & Bhattacharya, 2013; McClellan, Soucie, & Flanders, 1998; Plantinga et al., 2004). Between 2007 and 2010, outpatient dialysis social workers experienced an average increase of 7.6% in mean caseload size (Merighi, Browne, & Bruder, 2010).

NKF PEERS PROGRAM

The National Kidney Foundation's Peers program was developed in 2011 to provide support to stage 4 kidney patients, dialysis patients, and transplant recipients.

The first group of mentors was trained in August 2011, and the program was launched in September 2011.

Program Development

NKF Peers was created after conducting a needs assessment and thorough review of the literature and known peer mentoring programs, particularly in nephrology. There were no national peer support programs in nephrology to draw from, but there were a variety of local programs. The NKF of Michigan has been running a successful peer-support program since 1994, and was particularly instrumental in the development of the national NKF Peers program. However, the Michigan program provides support in person, and at

the national level this was not a possibility. The mentor training manual was adapted from the manual developed by the NKF of Michigan.

Some of the anticipated barriers to the long-term success and sustainability of peer programs for kidney patients were issues securing physical space, transportation, difficulty scheduling around dialysis treatments, and high staff turnover in dialysis units.

To help overcome some of these barriers, and to provide a program that would be accessible nationally, NKF decided to create a telephone-based peer mentoring program for kidney patients. Telephone-based support has been shown to be effective and beneficial in numerous patient populations, such as cancer (Colon, 1996; Mathews, Backer, Hann, Denniston, & Smith, 2002; Rudy, Rosenfeld, Galassi, Parker, & Schanberg, 2001), diabetes (Heisler, 2010; Heisler & Piette, 2005; Heisler, Vijan, Makki, & Piette, 2010), heart disease (Heisler, et al., 2007; Parry et al., 2009), depression (Travis et al., 2010), HIV/AIDS (Stewart et al., 2001), pain management (Arnstein, Vidal, Wells-Federman, Morgan, & Caudill, 2002), and other conditions.

CKD stage 4 patients, dialysis patients, and transplant patients were the initial target audience of the NKF Peers program. While all kidney patients would likely benefit from peer support, the unique challenges and particular emotional strain for those facing kidney failure and coping with life on dialysis or with a transplant were important factors in these groups.

Telephone-based peer support allows mentors and mentees to connect regardless of their location. It also allows pairs to be better matched, based on their needs, experiences, or demographic factors, such as age.

Program Overview

The NKF Peers program matches mentors and mentees one-to-one through a toll-free phone system. Interested mentees are matched with a trained mentor who has experienced a similar situation with kidney disease. Interactions vary in length per call and duration over time. NKF matches and tracks pairs via Inquisit Health's 1-to-1 Mentoring Platform (www.inquisithealth.com). This platform automatically provides toll-free phone numbers to mentors once they have accepted a new mentee match. The platform then tracks frequency and length of calls between pairs and automatically sends emails to seek feedback on the call from mentors and mentees once a call is completed.

NKF Staff

Since the program's inception, one full-time MSW has overseen and managed the program. About 40% of the staff member's time is allocated for management of the NKF Peers program. Additionally, two first-year MSW student interns assisted with the program.

MSW Role

The necessity of having an MSW clinician overseeing the NKF Peers program cannot be understated. A social worker's unique ability to assess a mentee's needs, history, and current situation (i.e., medical, support system, etc.) is an important part of successfully matching pairs. Additionally, an MSW's skills are imperative in providing training to mentors and support to mentors and mentees when difficult situations arise.

The National Association of Social Workers Standards of Classification considers the Master's in Social Work degree a specialized level of professional practice that requires a demonstration of skill or competency in performance (Anderson, 1986). This additional training in the biopsychosocial model of understanding human behavior enables the master's-prepared social worker to provide cost-effective interventions, such as assessment, education, and therapy, and to independently monitor the outcomes of these interventions to ensure their effectiveness (Browne, 2006).

All interested participants are interviewed, assessed, matched, and supported throughout their involvement in the program by a masters-level social worker (MSW). Mentees are supported by initial assessment of needs and frequent follow-up contact to ensure that matches are appropriate and meeting their needs. Additionally, the MSW provides psycho-educational information and appropriate resources to supplement the peer mentoring as needed. For mentors, MSW support includes regular communication about how matches with mentees are progressing, addressing any concerns regarding interactions with their mentees, and providing guidance on how to approach difficult situations. The MSW also provides ongoing emotional support for mentors who may be faced with their own emotional reactions brought up by mentoring relationships.

Recruitment of Peer Participants

Patients learn about the program through NKF's marketing efforts, which include flyers mailed to dialysis units, nephrology clinics, and transplant centers throughout the United States. Additionally, NKF mobilizes its professional members to share information about the program with their patients. Program information is also shared in NKF's various printed and online newsletters, blogs, and social media outlets.

Peer Mentor Selection and Training

Peer mentors are volunteers who express interest in being a mentor by reaching out to the NKF or applying online. Mentors undergo a telephone assessment by a masters-level social worker before taking part in an extensive telephone-based training program developed and provided by NKF.

The mentor training is based largely on the training program developed by the NKF of Michigan. This comprehensive mentor training program includes topics such as: confidentiality/HIPAA; values and beliefs; empathy; problem-solving; initiating, maintaining, and ending relationships; loss and grief;

cultural sensitivity; and more. There is a strong focus on role playing and group interaction throughout the training.

Initially the NKF Peers training was designed as 6 1-hour sessions with multiple attendees on conference call. However, after a few trainings it became evident that coordinating schedules for a group of mentors across the country presented a challenge. The training continues to cover the same material but is now 3 1.5 hour long sessions by conference call. This has improved attendance and has made scheduling easier.

Typically, a peer mentor training group will consist of 10–15 people. However, the largest group was 22 people, which proved to be too large to effectively accommodate by conference call. This was largely due to the fact that the training relies heavily on participation, interaction and role play, and, with 22 people, there was not enough time for each potential mentor to participate.

NKF hosts two trainings each year, which has adequately met the needs of the program as it has grown over time. Eighty of the 102 mentors trained completed all the requirements of training and became active mentors.

Mentors must have web access and an email address in order to access the online platform and to accept and track their matches.

Matching

NKF does not accept referrals from professionals to the NKF Peers program. Interested mentees and mentors must call or email NKF on their own accord.

After completing the mentee's assessment, the oversight clinician chooses an appropriate mentor based on the mentee's stated preferences. These preferences always include modality type (either current or what they are interested in), age, and gender. Additionally, some patients feel strongly about talking with someone who has the same cause of kidney disease. This tends to be important to those whose primary or cause of kidney disease has profound symptoms, affects their pre-ESRD health management, or who have had transplant-related concerns. Common causes of kidney disease that people specifically request talking about are: polycystic kidney disease, lupus, and diabetes, particularly for those with a kidney/pancreas transplant.

Every effort is made to find a mentor who best meets the mentees' needs. At times this requires having the mentee speak with more than one mentor.

How the System Works

To connect to each other, mentors are given a toll-free telephone number generated by the 1-to-1 Mentoring Platform (www.inquisithealth.com) to connect to their mentees. Neither party discloses their personal phone number or incurs long-distance charges.

The telephone system allows participants to talk directly with each other, leave voicemail messages, block calls at certain hours, and initiate reminder calls, if needed. Telephone services are provided free-of-charge by NKF.

During the interview and assessment of interested mentees, the oversight clinician documents their preferred availability. The oversight clinician chooses an appropriate mentor in Inquisit Health's 1-to-1 Mentoring Platform and an automatic email will go to the chosen mentor to ask if they are interested and available at the given times to talk with the new mentee. Once a mentor accepts the match, they are given a unique toll-free number and are able to call the mentee at any of the available times. Mentors always initiate contact with mentees. Times zones are always taken into account.

Mentors also have access to a "dashboard" with basic information on their mentees, as well as the toll-free number and available times. While mentees can call the toll-free number back if they miss a call, they will not be able to connect directly with their mentors, as it will not ring the mentor's phone. However, the mentors will be alerted that mentees tried to call them, and mentees are able to leave messages for their mentors.

DATA

Since its inception, the NKF Peers program has trained 102 peer mentors. 80 out of 102 mentors completed all the requirements of training and became active mentors. The program has connected over 423 people seeking support with peer mentors from September 2011 through December 31, 2015.

Demographic

Stage of Kidney Disease

Of NKF's mentees in the time period cited, 9% were CKD Stage 3, 38.5% were CKD Stage 4/5 not on dialysis, 35% were on hemodialysis, 11% were on peritoneal dialysis, and 5% had a transplant when they initially engaged with the program.

All mentors are either already on dialysis or have a kidney transplant. Mentors with experience in home hemodialysis, nocturnal HHD, peritoneal dialysis, in-center hemodialysis, as well as transplants from living and deceased donors are available. The program also includes mentors who have participated in paired exchange programs, or were listed for a transplant in multiple regions.

Age

Mentors and mentees range in age from 15 – 89 years old (See **Table 1**).

Gender

As of December 31, 2015, NKF Peers has 298 female and 124 male mentees, and 56 female and 48 male mentors.

Call Details

Since inception, NKF Peers mentor/mentee pairs have completed 2,111 calls. The average duration of calls is 26 minutes, with a range of 1 – 241 minutes. Excluding completed calls under 5 minutes, data shows an average call duration of 33 minutes (see **Table 2**). The average number of calls per matched mentor/mentee pair is 6.

Table 1. Age of Mentees

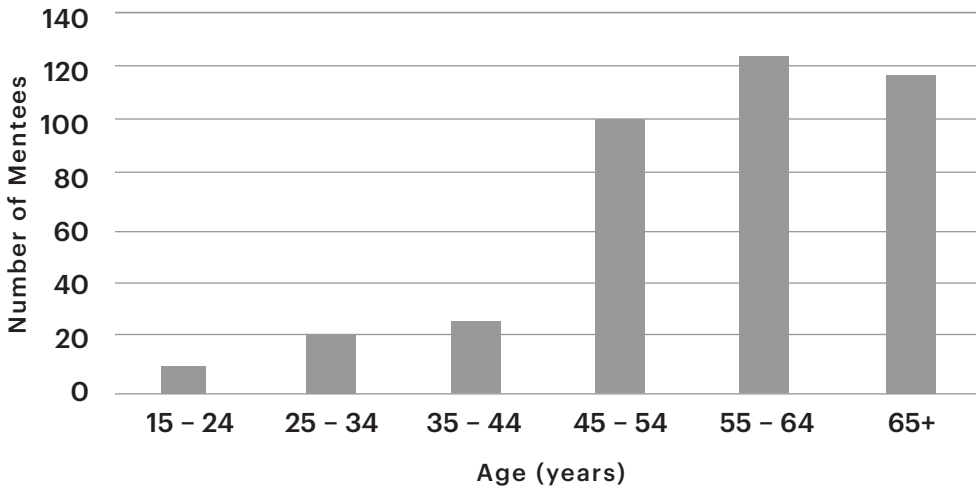
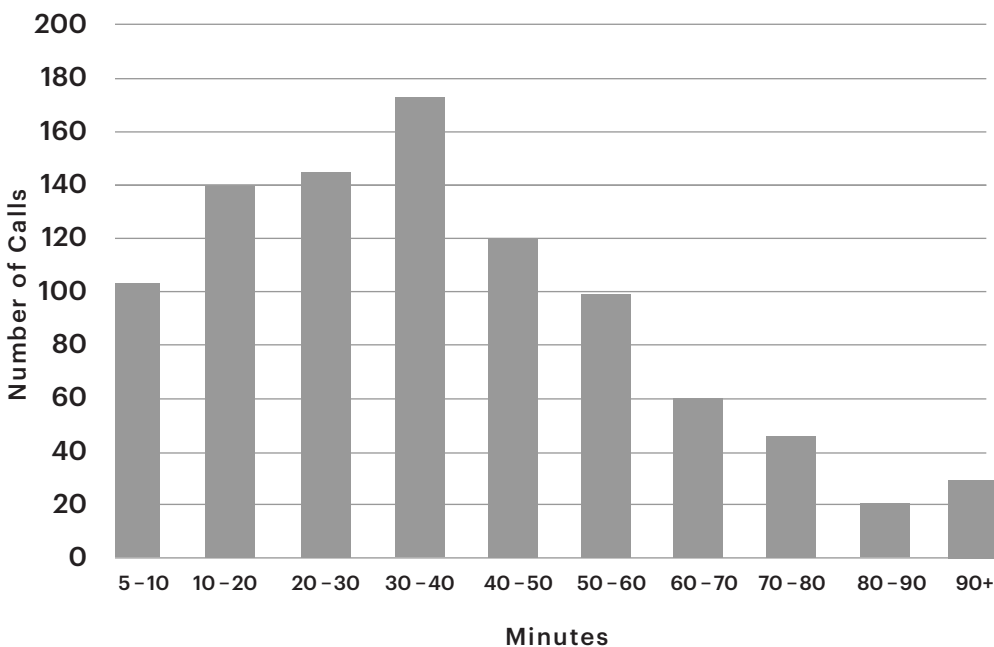


Table 2. Length of Calls (in minutes)



Mentor Training

The oversight clinician has facilitated 7 training sessions for new mentors since August 2011. The overall mentor evaluation for the training sessions showed that 100% of the trainees rated the training as “excellent” or “good.”

When asked to match their perception to the statement, “I feel well-prepared to be a peer mentor,” following training, 60% of the trainees designated “strongly agree,” and 40% designated “agree.” Evaluation data also shows that the telephone-based training format is effective and convenient, and that the information shared in the training sessions and training manual is “easy to understand,” “important,” and “valuable” to success as a mentor. In addition, the telephone format is successful in that there is significant interaction between trainees and NKF facilitators. Mentor trainees were fully engaged and participatory in the learning activities, discussions, and role playing exercises.

Mentors said they “feel proud” to be providing support to their peers, and “confident” in their skills as mentors after the training. They also expressed much enthusiasm for their new role.

Patient Activation Measure (PAM)

To measure knowledge, skills, and confidence for self-management, NKF utilized the Patient Activation Measure (PAM), developed by Insignia Health. The PAM is a valid, highly reliable, unidimensional, probabilistic Guttman-like scale that reflects a developmental model of activation. Activation appears to involve four stages: 1) believing the patient role is important; 2) having the confidence and knowledge necessary to take action; 3) actually taking action to maintain and improve one’s health; and 4) staying the course even under stress. The measure has good psychometric properties, indicating that it can be used at the individual patient level to tailor intervention and assess changes (Hibbard, Stockard, Mahoney, & Tusler, 2004).

Participants’ responses to the PAM translate into a numerical score, ranging from 0 to 100, which assesses a participant’s knowledge, skills, and confidence for self-management. The mean pre-participation mentor PAM score was 82.2, which demonstrated they have “made most of the necessary behavior changes.”

For our baseline measurements, mentees were asked to complete the PAM prior to being matched with a peer mentor. 405 mentees out of 423 interviewed (95.7%) for the program completed the pre-participation PAM. The mean mentee PAM score before being matched was 53.4, which indicated that they had “begun to take actions.” In the initial interview, mentees often expressed concerns about isolation and were looking for validation that their feelings were not necessarily unique. They also often expressed being “hopeful that things can get better.”

Both mentor and mentee pre-participation mean scores were consistent with NKF’s expectations and, especially for mentees, indicate room for growth and improvement in their knowledge, skills, and confidence in their ability to self-manage their healthcare.

NKF continues to collect post-participation PAM scores for mentees. Of the 405 who completed the pre-PAM, excluding the 57 patients still active in the program, NKF has received 146 completed post-participation PAMs (42%) to date. Those completed reflect an improvement compared with pre-PAM scores, with a mean of 65.96 demonstrating a significant improvement from average pre-scores (53.4), and indicating they have “made most of the necessary behavior changes.”

Mentee Satisfaction

After being matched with a mentor and completing the peer program, a survey is given to all mentees to assess their satisfaction with the program. The survey includes Likert scale(s) and open-ended questions. Mentees participating in the NKF Peers program were highly satisfied in their experience:

- 88% of mentees rate their overall experience with NKF Peers as positive (11% fair, 1% poor).
- 97% found their mentor to be helpful.
- 96% found their mentor to be supportive.
- 98% found their mentor to be knowledgeable.
- 97% would recommend NKF Peers to someone in a similar situation.

For those who were not satisfied with the program, issues identified were: problems with the phone system, particularly wishing they were able to initiate calls as mentees, preferring in-person mentoring, or not being matched with someone from their area.

Mentees express immense gratitude for the support they are receiving. Below are some examples of feedback:

- *My peer answered questions I thought were stupid, but I wanted an answer and she told me no question was stupid and gave me an answer.*
- *My mentor was extremely helpful with letting me know how she has moved through the process of diagnosis to PD to transplant. I hope I will be as successful as she has been with the process! Thanks so much to the NKF for helping me to understand some of the challenges that will face me down the road. It was extremely helpful to me and my family.*
- *Speaking with my mentor on a regular basis has been extremely helpful. She is very bright, helpful, and knowledgeable and speaks from experience. Since speaking with my*

mentor on a regular basis I have adopted a more positive attitude about being one of the millions of people living with CKD. I don't feel as negative and grim as I once did. I still struggle with my many dietary challenges; however, I have been utilizing many helpful resources, including NKF. Having a positive role model has made incorporating the renal-diabetic dietary guidelines much easier. I don't feel as alone coping with kidney disease as I once did. Overall, I feel that having an NKF peer has been an extremely rewarding and positive experience in my life as a kidney patient. Thank you so much.

- *It was easy to use and the people involved seem to be knowledgeable about the health concerns. The program was also free to the person who needed support and NKF was readily available and positive to my feelings and concerns.*
- *I could let my hair down with my mentor. I could talk to a real person who had gone through the things I am facing — dialysis and transplant. There is nothing better than receiving support from a person who has (or is having) similar experiences to your own.*
- *The best part of the NKF Peers program was the opportunity to talk to someone my age and in similar circumstances, and also already on dialysis...gave me an idea of what I could expect for myself in the near future.*

POTENTIAL CHALLENGES

Telephone-based Peer Mentoring

Both mentoring and training by phone pose unique challenges. While some people value the anonymity of phone-based peer mentoring, others prefer face-to-face connections. Some even go a step further and feel strongly about talking with someone from their local area, state, or region of the country. There are others who are specifically seeking a group setting so that their families can join, or because they feel more comfortable in a group where they can potentially be a listener, versus a more vocal participant.

Calls between mentors and mentees are not monitored or recorded. Where a support group may be facilitated by a licensed clinician, one-on-one peer mentoring, particularly by phone, precludes the level of oversight some practitioners believe to be optimal. However, the numerous successful uses of telephone-based peer programs reviewed in the introduction, as well as the NKF Peers program itself, demonstrate the relevance of such programs and the capability of patients as peer mentors. Additionally, when taking into consideration the benefit of accessibility that a telephonic program offers to patients, regardless of their location, the value is further illuminated. Furthermore, NKF's robust, comprehensive mentor training, MSW oversight, and ongoing quality assessment are important factors in the ongoing success of the program.

Technology

Initially, NKF Peers utilized a toll-free phone provider that allowed NKF to buy as many toll-free numbers as needed and manually route calls according to matches. While this system initially met the needs of the program, as the program grew it became increasingly time consuming to manually set up call routing and track matches.

In April 2015, NKF moved to a new online peer management platform through InquisitHealth. This platform allows the oversight clinician to match and track pairs throughout their participation in the program. The system also automatically provides a toll-free number for each mentor/mentee pairing.

Enhanced technology has greatly improved the ability of the NKF oversight clinician to manage large numbers of pairs in varying stages of the mentoring process. As any successful program grows, technology will be important to support growth. InquisitHealth continues to be an ideal partner in being open to tailoring the platform, based on the program's evolving needs over time.

However, despite the benefits and necessity of technology, participants also highly value the direct person-to-person contact by phone. This is true both of the mentor/mentee relationship, as well as the oversight clinician/mentor and mentee relationships.

Anticipating Growth – Staffing

While one NKF staff member has managed the program to date (comprising about 40% of their time), the future success of the program is dependent on growth. This growth will necessitate additional staff time and/or additional staff.

Even with improved technology in place, the level of follow-up and tracking required is immense. Following pairs throughout the different stages of their interactions requires regular communication with both mentor and mentee, and comprehensive documentation. Administrative support staff could assist with follow-up calls, emails, mailings and surveys. This may improve completion rates of post-follow up surveys and PAM questionnaires.

Anticipating Growth – Mentors

Initially, NKF was cautious about promoting NKF Peers too widely before enough mentors were trained. Maintaining the right amount of mentors to accommodate the influx of mentees is a constant balancing act.

Additionally, making sure to have enough of the “right type” of mentors is important, and can change over time. This means anticipating why people will call looking for support. For example, as demonstrated in the age range for mentees, a large proportion of those seeking support are aged 45–64. Although NKF may receive interest from many mentors who are under 45, it would not be prudent to train too many young

mentors unless the participation of mentees in that age group increases. We aim to provide a core group of mentors with experience in different modalities across age ranges.

Also, training too many mentors can also be problematic. Mentors who are trained and then not utilized results in once enthusiastic, valuable volunteers feeling deflated and let down. This has been especially notable in a large portion of interested volunteers having preemptive transplants. While their experience is valuable, the majority of mentees reaching out to the program are looking to speak with someone who has also had dialysis experience. Training too many mentors with preemptive transplants does not benefit the program, and often these mentors feel neglected and under-utilized.

Attrition

There is a natural attrition of mentors due to changes in their personal health, family life, or careers. There are also very well-intentioned peer mentors who underestimate the amount of free time they have to offer and end up being unable to participate in a meaningful way, despite completing the training. For these reasons, it can be difficult to gauge how many successfully trained mentors will be ongoing peer mentors. Providing bi-annual trainings for new mentors has maintained a core group of active mentors throughout the year to adequately accommodate the current volume and needs of mentees contacting NKF Peers for support.

THE FUTURE OF NKF PEERS

As NKF Peers continues to grow, NKF will continue to train new mentors and match them with appropriate mentees. NKF hopes to eventually expand the program to provide support to other groups, such as early-stage CKD patients, care partners, families, parents, and others.

Recent Expansion for Living Donation

As of October 2015, the NKF Peers program began matching living kidney donors and prospective living donors with trained peer mentors who have already gone through the kidney donation process, providing a place for altruistic individuals to discuss concerns and address questions.

NKF worked with their Living Donor Council Executive Committee, along with additional living donors and Living Donor Advocates, to create and develop this program. Training materials, as well as mentor and mentee assessments and tools, were based on the NKF Peers program, but were tailored to meet the specific needs of this population.

Ongoing Support for Mentors

While NKF's oversight clinician provides support individually to peer mentors, NKF does not currently have a standard process for providing ongoing support to the mentors as a group. In the future, NKF is looking to formalize ongoing training and support for mentors. This would allow mentors to connect with each other for support, to share their experiences as mentors and discuss common challenges/issues that arise, either via conference call or an online platform.

Ongoing Support for Mentees

Once mentees complete the NKF Peers program, many would like to find a way to keep in touch, or to be able to connect to others in a semi-structured way. Many mentees note that they would like the opportunity to continue to keep in touch with their mentors by email after it is determined that they no longer need regular calls.

NKF will continue to look for opportunities to connect people in different ways. However, NKF is committed to telephone-based peer support being a central feature of the NKF Peers program.

CONCLUSION

NKF Peers has demonstrated success during its initial four years, with a notable change in pre- versus post-PAM scores, as well as highly positive participant feedback. NKF looks forward to both continuing and growing this successful program, and continuing to provide support to those affected by kidney disease.

Social support for people living with kidney disease and kidney failure is imperative. Peer support for those with chronic illnesses has been shown to improve depression, social isolation, self-esteem, and self-management, which in turn increases involvement in care and overall health and well-being. Despite well-established and growing evidence of the efficacy of peer support, the availability of such programs is lacking in the kidney community.

We encourage nephrology professionals to share information about NKF Peers (1.855.653.7337; nkfpeers@kidney.org) with their patients and to reach out to this writer with any questions about the program. NKF offers free marketing materials to share with patients, which can be sent to clinicians free of charge upon request at www.surveymonkey.com/r/freenkf.

In addition, we hope our successes and challenges are helpful to others developing or running peer support programs for patients with chronic disease.

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**Sometimes,
just talking to
someone
can make all the
difference.**



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