

# Trained ESRD mentors: an important resource for total patient care

## A project of the Kidney Foundation of Central Pennsylvania

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### Introduction

When a doctor informs a patient about an ESRD diagnosis, it is a shocking, “it-can’t-be-me” moment. Even the terminology “end-stage” evokes visions of a bleak future—or no future at all. People diagnosed with kidney failure and their family members face significant changes in their daily lives. Most often, newly diagnosed patients feel extreme apprehension and fear of the unknown. The complexity of information conveyed regarding renal disease management can be overwhelming. Those who endure years of treatment or years of waiting for a kidney transplant may become discouraged and emotionally drained. They may also suffer physical complications from their treatment. A full team is available to support a person with kidney failure, including a nephrologist, nurse, patient care technician, renal dietitian, and social worker. However, support from someone who has gone through the same experiences can be very influential in the success of a person adapting to kidney failure and not succumbing to maladaptive behaviors, poor quality of life, and living just as a patient.

Despite the challenging situations people with kidney disease face, those who learn to cope well with their disease can help to motivate others in similar circumstances as the latter work to clear the hurdles placed before them. Those who have navigated the obstacles successfully can also benefit from giving back to others through empowering and empathetic exchanges. The positive attitudes and learned coping mechanisms some people can share with mentees can help to motivate the latter and bring about significant improvement in outcomes. Social workers and medical team members can educate and encourage people to live a full and happy life in spite of having kidney failure, but what is profound is the value of providing supportive role models

who demonstrate by example that there can be good quality of life after ESRD.

Inspiring stories coming from the The Kidney Foundation of Central Pennsylvania (KFCP) Patient-Partner Program (PPP) are motivational to the professional caregivers as well as to the other patients in the clinics. The people behind these stories have so much to offer the renal community and the individuals touched by the program. They bolster the need for and illustrate the benefits of a well-designed and properly monitored mentor program.

### Separating mentoring from advising

Patient mentors are taught the parameters of the mentor role and their activities do not interfere with the patient/medical team relationship. They are not permitted to address medical and psychosocial issues a person may face when diagnosed with kidney failure. Conversely, the emotional support offered by a trained patient mentor cannot be replaced by education and support provided by clinical staff. A supportive relationship between the medical team and the PPP coordinator can bolster efforts to assist the patient.

### Getting the program started

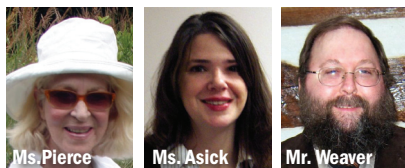
A volunteer board of directors whose membership includes renal professionals, community leaders, and corporate professionals guides The KFCP. Three of the directors with medical backgrounds are also kidney transplant recipients who add the voice and perspective of those with ESRD. One of those directors planted the seed for this program in the wake of an unsuccessful search for effective emotional support when her own kidneys were failing.

A small steering committee (SC) was formed to discuss the feasibility of launching what was termed, from the outset, the Patient-Partner Program. This committee, including a renal social worker, a transplant coordinator, and a nurse/kidney transplant recipient, had the following two-fold mission:

- *Establish the goal and objectives of PPP*

The goal of PPP is to offer the central Pennsylvania medical community the volunteer services of patients and caregivers who are certified by The KFCP to provide appropriate emotional support to patients and caregivers in need (see Table 1—Objectives of the PPP).

- *Develop a design and structure for PPP*



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kidney-transplant recipient. **Ms. Asick** is a dialysis social worker at Fresenius Medical Services, Northeastern Pennsylvania. **Mr. Weaver** is the staff coordinator, Patient-Partner-Program Expansion Project for The Kidney Foundation. The KFCP was established in 1979 and serves 28 counties in central Pennsylvania.

**TABLE 1****Objectives of the Patient-Partner Program**

1. To complement the care given by medical and allied health professionals (not to interfere with it)
2. To provide an environment in which a mentee is able to explore concerns and ask questions of a Certified Partner, thus helping a mentee to adjust to living with kidney failure
3. To foster a good working relationship amongst professionals and the PPP volunteers via the liaison role of the PPP coordinator

The SC conducted a search to find existing mentor programs available to renal patients. A thorough Internet search and phone calls to the National Kidney Foundation (NKF), regional renal networks, and other renal resources yielded only one program entitled “Patient-to-Patient,” a program of Indianapolis-based The Renal Network, Inc. Their program manual included the Do’s and Don’ts of mentoring, the characteristics of an effective mentor, and other guiding principles. The SC obtained the “Patient-to-Patient” program handbook, which served as an effective starting point for our program’s development.

The SC presented the mentor program concept to medical professionals and sought their input. Discussions with nephrologists and social workers revealed concerns on several fronts. At first, members of the SC were taken aback by the initial cool reception to the patient-to-patient mentoring concept. Our awareness of concerns allowed us to incorporate potential solutions as the program design developed. Obviously,

having the cooperation of renal professionals was essential to PPP’s success. Concerns voiced and solutions proposed by the SC were as follows:

*1. Individuals whose personal health is compromised may be unwilling or unable to commit the time necessary to complete mentor training and then be available as a reliable source of emotional support for others.*

PPP will seek professional input to select people whose health is reasonably stable and who have nurturing characteristics. Identifying caring, altruistic people has not been difficult. The level of commitment is carefully explained to volunteers prior to training.

*2. Mentors may see this as an opportunity to share personal horror stories, thus having a negative impact on mentees, or they may try to provide medical advice.*

Having renal professionals refer people for PPP training provides the initial stage of the selection process. One of the major reasons mentors should be trained is to stress that the focus is on the mentees, not the mentor. Robert Louis Stevenson’s quote helps to convey our central program philosophy: “Keep your fears to yourself, but share your inspiration with others.” PPP training emphasizes that everyone’s situation is different, so comparison is inappropriate. Medical teams should be made aware of the focus of the training. Then they must take the leap to participate in the PPP in order to be convinced that mentoring with proper oversight works.

*3. Renal professionals may be reluctant to regard PPP as a reliable resource due to their concerns.*

*a. Trained mentors from different practices may try to lure mentees to their personal medical teams.*

To address any concerns of medical professionals about having mentors from other practices assigned to their patients, PPP is conducted as an intra-practice program; that is, trained mentors are assigned only to patients and caregivers from the same medical prac-

tice. Exceptions are made only with prior approval of the mentee’s nephrologist.

*b. Volunteer programs come and go. How long will this one last?*

The only way to build confidence in the PPP’s longevity is to recruit reliable volunteers who demonstrate dedication through their actions, with built-in plans to ensure the program’s longevity. The volunteer PPP Pilot Program Coordinator has been a very active KFCP volunteer for more than 15 years. Nevertheless, PPP’s reputation must be built one partnership at a time.

*4. Insufficient numbers of people may seek assistance from other patients to justify the effort.*

PPP will be offered to all ESRD patients through their medical professionals, recognizing we must build a track record over time. Patients will most likely not be receptive to having a mentor while they are in the shock, denial, or anger stages. More success may come when patients are approached once they are motivated to seek and accept help.

**Standardizing the training process**

A 17-member, multi-discipline PPP Curriculum-Development Committee (CDC) was formed. The goal and objectives of the PPP training program were set forth by the CDC. The goal of PPP training is to educate certain ESRD patients and caregivers to mentor others affected by kidney failure in accordance with PPP policies and guidelines (see Table 2—PPP Training Objectives). Consensus was reached regarding characteristics and criteria for PPP trainee candidates, training parameters, session topics, target educational level for training materials, and other guiding factors. The CDC, consisting of one adult and one pediatric nephrologist, one transplant surgeon, three renal nurses, three renal social workers, one renal dietitian, one transplant coordinator, one chaplain, one psychologist, three well-informed ESRD patients with renal transplants, and one supportive care-

## TABLE 2

### Objectives of PPP training

1. To strengthen trainee's confidence and knowledge regarding their own disease, treatment options, and their effects on lifestyle
2. To teach trainees the Do's and Don'ts of mentoring
3. To help trainees develop effective communication and listening skills
4. To provide information to trainees regarding local, regional, and national educational resources as well as social and financial-support resources

## TABLE 3

### The KFCP Patient-Partner-Program training curriculum

- ▶ Patient-partner role
- ▶ Communication and listening skills
- ▶ The support team
- ▶ ESRD 101
- ▶ ESRD effect on family relationships
- ▶ ESRD effect on sexuality
- ▶ Special needs of children and adolescents
- ▶ Special needs of the elderly
- ▶ Kidney transplantation
- ▶ Renal diet
- ▶ Responsibilities of the medical team and the patient
- ▶ Social and economic needs of an ESRD patient
- ▶ Community resources
- ▶ Choices
- ▶ The visits—role playing

giver, accepted assignments for curriculum sections aligned with their respective areas of expertise. Over the course of the 2003-2004 fiscal year, drafts were submitted, edited, and reviewed by curriculum writers until the curriculum reached its final form in August 2004. (See Table 3—PPP Training Curriculum). In the meantime, PPP Trainee-recruiting packets were developed for mailing to renal professionals with a cover letter explaining the program in detail.

#### Implementing PPP training

As a training session date approaches, renal professionals are requested to put the information packets in the hands of patients they believe to be appropriate candidates for mentor training. The packets include an introduction to PPP, course overview, a target mentor profile (See Table 4—PPP Candidates Preferred Profile), and an application that includes a brief questionnaire. Prior to enrollment, a member of the PPP Advisory Committee interviews each applicant.

PPP trainers are recruited from the professional world—some from the CDC and others from the community at-large. PPP trainers volunteering their time not only provide a beneficial service; they also become involved in

and advocates for the Program, with raised awareness of its high quality and potential benefits.

PPP trainees must evaluate each curriculum section. An unsigned evaluation form is completed and submitted to the PPP coordinator at the following session. Evaluations are reviewed by the PPP coordinator and discussed with PPP trainees at the beginning of the next session. Suggestions that have positive reception are implemented as soon as possible.

#### Launching partnerships

At the final session of the Patient-Partner-Program Training, The KFCP provides each trainee with a certificate acknowledging completion of the 16-hour curriculum. The new Certified Patient Partners (CPPs) and Certified Caregiver Partners (CCPs) provide the PPP coordinator with contact information for members of their respective medical teams. The PPP coordinator, in turn, notifies the nephrologists, transplants surgeons, social workers and renal nurses that their patients have completed training and are available for partnering with ESRD patients seeking companionship and emotional support. When a patient is referred to the program, the PPP Coordinator works with the referring professional to identify the best possible match. Consideration is given to gender, age, and treatment-modality experience.

PPP policy is to allow the mentee to drive the relationship. Partnerships are maintained for three to 12 months (more in some situations), depending on the needs of the mentee. If for any reason either the CP or the mentee is not comfortable with the relationship, another partner will be assigned to the mentee. The recommended frequency of contact by CPs is once a week by phone, with a personal visit at least once per month. The KFCP underwrites the costs of partnership lunch meetings when the mentee prefers to meet in a neutral location.



Class of 2005 Certified Patient Partners: (back) Jamaar McBride, Olivia Boswell, Mark Johnston, Marcy Saunders; (front) Rochelle Johnston, Rodger Harris

## TABLE 4

### Patient-Partner-Program candidates preferred profile

#### People who have “been there” because

- ▶ They have kidney failure and are either on dialysis or have received a transplant, and are well-adjusted to their disease, or
- ▶ They have provided effective emotional support for a family member or a friend with kidney failure

#### Patient-Partner candidates should have

- ▶ Good emotional health
- ▶ Good coping skills for dealing effectively with one’s own illness
- ▶ A positive attitude and approach to life
- ▶ A sense of humor
- ▶ Concern for others and desire to help them

#### Certified Partner candidates should be

- ▶ Mature, friendly, flexible, dependable
- ▶ Compliant with one’s own treatment, medication, diet, etc.
- ▶ Aware of personal strengths and weaknesses
- ▶ Knowledgeable about one’s own limitations
- ▶ Willing to learn
- ▶ Able to communicate effectively with others
- ▶ Respectful of individual feelings, attitudes, and differences
- ▶ Available to offer support needed for an assigned patient and his or her family
- ▶ Able to maintain confidentiality
- ▶ Able to provide one’s own transportation to visit mentees

The PPP coordinator is responsible for overseeing partnership interactions. CPs submit to the PPP coordinator brief, confidential contact reports for each substantive phone conversation or personal visit, highlighting the points of discussion, special concerns raised by the mentee and the CP’s plan for the next contact. The PPP coordinator also serves as liaison to the mentee’s medical team, contacting the social worker when issues raised seem life threatening or in other ways harmful for the mentee.

#### Continuing education

The PPP coordinator sets up quarterly “refresher courses” to help maintain a high bar for program quality through continuing education. Periodically, guest facilitators—renal social workers, nurses, psychologists, or other appro-

priate professionals—help to facilitate discussion as CPs relate actual partnership scenarios and experiences. Do’s and don’ts of mentoring are reviewed and focus is given to the use of appropriate communication and listening skills. The charter group of CPs helped to establish the policy that each CP must attend a minimum of one refresher course per year in order to maintain certification.

#### Measuring partnership outcomes

The quality and effectiveness of PPP is monitored through a tri-level evaluation process. Renal professionals, CPs, and mentees are asked to complete evaluation forms to reflect what they feel is beneficial about the program as well as to offer constructive criticism and ideas for improvement. In cases where mentees are not able to write

## PARTNERSHIP SCENARIOS

### ESRD and home life

Rick started on hemodialysis after a long history of complicated medical issues. Wheel chair bound, he seemed resigned to a life plagued by poor health and dependence on his wife Sharon to manage his daily life. Sharon became very stressed and anxious. Facing her own serious health challenges, she felt she was barely keeping her head above water before Rick’s kidneys failed. She could not imagine coping with the added burden of having her husband on dialysis. Sharon was referred to the PPP. Paula was assigned as her mentor. At the initial meeting, Paula felt Sharon had significant mental health issues and feared for Sharon’s life. Paula contacted the PPP coordinator who immediately contacted Sharon’s physician and social worker. Sharon followed her physician’s instructions to go to the local emergency room where she was treated for mental distress. Sharon’s medical history revealed that she had long-standing mental health issues. A mental-health case manager was assigned and respite services were prescribed for Sharon. A family member flew in to care for Rick while his wife’s personal health issues were addressed. The staff at the dialysis unit would have likely learned Sharon’s limits before she would resort to drastic measures, but this would have placed Sharon at great risk. Starting dialysis is a challenging time for both the “patient” and the family. The collaborative relationship between the PPP and the renal team enhances the care offered to the people affected by kidney disease.

## PARTNERSHIP SCENARIOS

### Seeing is believing

Maryann's creatinine and BUN were rising steadily. Her nephrologist wanted her to start dialysis. She considered refusing dialysis and ending her battle with ESRD. A member of her medical team referred her to the Patient-Partner Program, requesting that a Certified Partner (CP) be assigned to provide encouragement. Michelle, the CP assigned to Maryann, had been on hemodialysis for more than three years and was awaiting a kidney transplant.

Upon first meeting, Maryann expressed surprise when she saw how healthy Michelle looked. She shared with her CP that she had not yet told her family about her kidney failure. Knowing how much people with chronic disease benefit from the support of family and loved ones, Michelle encouraged Maryann to inform her family as soon as possible. At the end of their visit, both Maryann and the CP agreed to meet again.

A few weeks later, Maryann reluctantly started dialysis at the same center where her CP dialyzed. Their relationship continued to grow. During the next few months, Maryann accepted dialysis and acknowledged that she felt better when compliant. The CP observed that Maryann's entire attitude had changed. She began smiling, became animated and finally informed her family members of her condition. She repeatedly said that her CP had made a big difference in her life. In spite of moving out of state to be closer to family, Maryann calls her CP occasionally and continues to express gratitude for the emotional support provided by her competent mentor.

their opinions, social workers assist them in completing the form.

Evaluation-form return rate has been limited, but frequent discussions with referring physicians and social workers provide useful feedback for the program and help the PPP coordinator to build rapport with the medical teams.

#### What's in it for the CPPs and CCPs?

A question raised recently at a PPP presentation to medical professionals was, 'What's in it for the CPs who obligate themselves to 16 hours of training, weekly phone calls and monthly visits to mentees, contact-report requirements, and quarterly refresher courses?'

Certified-Partner evaluations, discussions at quarterly refresher courses, and PPP coordinator direct observations have revealed tremendous bonding amongst CPs. Living with ESRD themselves, they still face the myriad of challenges presented by chronic kidney disease. They save constructive discussion of personal trials and challenges for each other, with the benefit of a renal-professional facilitator in attendance. This helps to ensure that personal issues experienced by CPs will be vented and addressed prior to a CP's meetings with his or her mentees. Thus, a wonderful benefit not anticipated when this project first launched has been realized.

Most people reading this know the deep satisfaction that comes from helping people by providing a needed service. Find people who thrive on altruistic contributions of personal time and service, and you have gathered a very special group of individuals. They not only find satisfaction from their individual efforts; they also sense the importance of the entire team and its role in creating and sustaining a successful program. The training they receive provides useful education, giving them a deeper understanding of kidney disease and its effects on themselves and those around them. They learn—and practice through role-play—positive

ways of communicating and listening that are applicable to all aspects of life and interpersonal relationships.

#### Tracking PPP statistics for the Greater Harrisburg Pilot Project

Currently, PPP services are available to patients and families associated with seven nephrology practices, eight hemodialysis centers (collectively dialyzing about 565 patients) and two renal-transplant centers in a three-county area of Greater Harrisburg. To date, 27 CPs have been trained and certified by The KFCP. Each class is small (maximum eight to 10) by design to allow for adequate individual attention. We are now up to 50 mentee assignments.

#### Mapping program expansion

The favorable outcomes of the KFCP PPP pilot project and positive feedback from renal professionals made it clear to The KFCP Board of Directors that the PPP needs to be expanded to serve The KFCP's entire 28-county constituency. The PPP Coordinator for the Pilot Program is a volunteer. The time and consistent attention required to oversee expansion led The KFCP to hire, in January 2008, a part-time staff PPP Coordinator. Fresh out of the gate, the new PPP coordinator created and published a newsletter featuring nephrologists and social workers that have championed the program and sharing testimonials of people who have benefited from PPP mentoring services. Using a map of the region, the new coordinator divided The KFCP service region into smaller segments based on geography and the population of the counties. This facilitates management of target areas and allows for efficiencies when meeting with renal professionals from each area.

#### Spreading the PPP story to renal professionals

The PPP coordinator contacts renal social workers to explain and build interest in the PPP. Generally, the con-

## PARTNERSHIP SCENARIOS

### Partnership paves way for PD success

After three years of in-center hemodialysis treatment, Lucious Livingston lost access to his fistula, which meant hemodialysis was no longer an option. Livingston was hesitant to transition to peritoneal dialysis because he was worried about how it might affect him and what problems he might encounter with this new treatment. However, with the help from Fresenius Medical Care social workers and The Kidney Foundation of Central Pennsylvania's Patient-Partner Program, Livingston was encouraged to give peritoneal dialysis a chance.

To help Livingston adjust to the changes affecting his treatment, he was matched with Certified Partner Don Clark, a former Fresenius Medical Care peritoneal dialysis patient in Carlisle, Pennsylvania. The two met in 2005 to discuss his treatment options.

During Clark's first visit, he showed Livingston his peritoneal dialysis catheter site and dialysis supplies, and spoke about his own successful transition to peritoneal dialysis. After visits to Livingston's house, Clark continued to call and check in on Livingston's peritoneal dialysis progress. Clark felt great satisfaction in helping Livingston with his new treatment decision.

"I didn't want anyone else to feel the way I felt when I was hit with a similar decision about dialysis," Clark said. After two successful years on peritoneal dialysis, Livingston received a kidney transplant in December 2008.

fact person organizes a meeting with decision-making members of the local renal team—physicians, social workers and nurses. The PPP Coordinator presents the "PPP Story" and provides a copy of the training curriculum manual. The renal team then decides whether to establish a PPP satellite program.

Establishing a new PPP requires the commitment of a satellite coordinator, one who oversees the recruitment of PPP volunteer trainers and trainees

central Pennsylvania, thus making it possible for CPPs and CCPs to touch more lives as the number of people facing ESRD continues to grow.

#### Summary

The KFCP recognized a need for a mentoring program utilizing patients who have been trained to provide appropriate emotional support and practical tips to others facing the challenges of ESRD. A pilot project was developed by renal professionals and ESRD patients

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as well as assignment and monitoring of partnerships. The KFCP supplies curriculum materials, and underwrites program expenses. The PPP coordinator serves as a consultant and guide throughout the process, teaches the opening class and presents The KFCP certificate at the final session.

#### Planning outreach throughout central Pennsylvania

In the years to come, we will work to make the PPP available throughout central Pennsylvania. With 56 dialysis centers in our constituency, PPP can reach over 3,300 hemodialysis patients alone. Of course, PPP will also be made available to people treated with peritoneal dialysis as well as kidney-transplant recipients, and their caregivers. The first satellite program has been established in Montour County, Pennsylvania. The plan is to establish four more satellite programs over the next 12 months. Discussions are under way in several large counties. The KFCP will continue to chip away, region by region, to expand the PPP throughout

using a systematic approach to develop a curriculum, recruit qualified ESRD patients and caregivers, provide mentor training, and match CPs and mentees. An effective tool in other health disciplines such as American Cancer Society and Hospice, this mentoring program filled a gap in resources available to renal patients. The success of The KFCP PPP Pilot Program in the greater Harrisburg, Pennsylvania region (covering three counties) has led The KFCP to conclude that the PPP should be available to its entire 28-county constituency. Creating a KFCP staff position of PPP Coordinator has set the stage for the same methodical expansion of the program as human and financial resources allow. The KFCP has created a model that can be emulated throughout Pennsylvania and beyond. All ESRD patients and affected loved ones deserve the support of a mentor who has learned to cope well with the challenges presented by chronic kidney disease. The PPP ensures that the support provided is appropriate and beneficial. **N**