In the September 2002 issue of NN&I, I wrote the article “Patients educating patients: Let’s add a little PEP to the community.” The concept of “patients educating patients” was developed from the certainty that the nursing shortage—coupled with the demanding workload of physicians, dietitians, and social workers—would have a negative impact on patients. I asked myself: “Who would be available to meet the educational needs of the rapidly growing population of kidney patients?” In my mind, there was only one plausible answer: the patients. So, for the past few years I have been pitching the idea of Patients Educating Patients & Professionals to the renal community.

PEPP is a series of educational programs to be led by patient speakers. Its goal is to improve the outcomes of CKD patients by increasing their knowledge of their disease, thereby encouraging involvement and self-management in their care. Initially, the programs will focus on anemia, secondary hyperparathyroidism, and adherence to the patient care plan. Behind-the-scenes work will involve development of educational materials to help patients understand the nuances of their disease, training a core group of patient educators, and providing tips on how to help health care professionals help patients adhere to their care plan.

PEPP will be set in motion by 15 chronic kidney disease patients who express interest in educating fellow patients and in sharing insight with health care professionals on how to best encourage patients participating in their own care. Following face-to-face speaker training, education on the program topics, and conference calls to reinforce training, speakers will be marketed (via promotional literature, meeting planners, websites, etc.) to help secure engagements at local and national professional and patient meetings. PEPP speakers will be asked to address the impact to the patient of dialysis related disease states and adherence to the care plan, impart tips for improving patient health and well-being, and share their own stories. In addition, they will be serving a dual role: They will be models of hope to the renal patients and professionals they encounter during their speaking engagements.

Any illness—particularly end-stage renal disease—is too demanding when you don’t have hope. If ESRD patients do not believe they have a future, then the demands placed upon them by dialysis will be overwhelming. Why would patients be interested in adhering to a care plan if they felt that they would not be around in a few years to reap the benefits? PEPP is built on the cornerstone of patients better adhering to their care plan and becoming more self-sufficient once they see other patients achieving their goals and dreams in spite of renal disease. By witnessing even one example of a successful patient, other patients might latch onto that motivating energy and realize that they, too, have a future.

Patients helping patients

CKD patients are often handed a brochure telling them how to make the most of their lives. The PEPP speakers, by contrast, will be living, walking proof that kidney problems can be overcome with hope, an eye toward the future, a working knowledge of the various disease states, and a touch of common sense. The PEPP speakers will provide reassurance to their audiences that while CKD patients might have lost their kidney function, they did not lose their identities or the ability to take an active role in their care.

Reading materials will be sent to potential PEPP speakers prior to convening in Los Angeles for a three-day training session (to be held in late January) so that all participants will be starting from a similar baseline. Upon completion of the training, follow-up conference calls, and individual coaching will help ensure this pilot program evolves and that individuals are given the tools necessary to succeed.

To arrange for patient speakers from the PEPP program, contact Renal Support Network at info@RSNhope.org; www.RSNhope.org; phone 818.543.0896.