

3. Goal 2 - C. Resources & Opportunities for Beneficiaries

1. Educational Information & Activities.

To encourage independence, improved quality of life, and self care and transplantation, the Network continuously works to promote understanding of end-stage renal disease and its impact on the ESRD patient and family. The following activities were conducted during 2006.

- New patients were informed about the Network through a New Patient Packet that the Forum distributes to new patients. The Network updated its letter in 2006.
- Patients participated on Network committees including the Board of Trustees, the Medical Review Board, and the Patient Leadership Committee (PLC). Throughout the year, information about the PLC and Patient-to-Patient Program as well as other patient resources were sent to patients and staff who expressed an interest in becoming involved with any of the programs.
- Patients participated in the Robert Felter Memorial Award program, both in choosing the recipients for the facility and patient awards as well as educating and sharing with fellow patients after being the recipient of the award.
- Both the CAHPS information and the KDQOL are posted to the Network Web site to assist facilities in developing mechanism for assessing the health-related quality of life of their patients.
- The Network developed a brochure regarding its Technical Assistance Program and distributed it at patient and facility meetings and events.
- A new brochure entitled “How Do I Look” (Taking the Fear out of AV Fistula Placement) was available to patients and staff.
- The Ease the Ouch brochure continues to be given to patients and staff to help with fistula placement.
- Two patient education programs were presented in December in Indianapolis, focusing on anemia education.
- Patients were given DFC cards at meetings held by the Network and facilities were given DFC posters and cards at Network meetings and at events where the Network had exhibit booths.
- The Network Web sites provided the Guidelines for Assessment and Referral to Vocational Rehabilitation for Patients, other vocational rehabilitation resources,

The Renal Network, Inc.
2006 Annual Report – ESRD Network 9/10

transplantation, treatment modalities, advance directives, and other end of life issues.

- The Network patient Web site offered vascular access videos, which were converted to Flash File format for easy viewing and downloading.
- The Network resources on quality of life were sent when requested and were available for download from the Network Web sites.
- The Network participated in the American Kidney Fund's Regional Conference in Chicago in November and staffed an exhibit providing handouts on treatment modalities, quality of life, grievance process, access, and Dialysis Facility Compare.
- The Network sent information to social workers about National Donate Life month and a list of links to transplant-related Web sites.
- The Network participated in the NKF Stuart Kleit Annual Symposium in Indianapolis in December and staffed an exhibit providing information on quality of life, DFC, grievance policy, and fistula-related issues.
- The Network Web site contains links to resources, such as the KDQOL and the Consumer Assessment of Healthcare Providers and Systems (CAHPS) which facilities can use to evaluate and improve patients' satisfaction with their care.
- *Renal Outreach*, a newsletter dedicated to the individuals with end-stage renal disease, was published twice during 2006. The list of articles included the following stories: Rehabilitation Starts with a State of Mind, It Was All in a Smile (vocational rehabilitation story), Frequently Asked Questions about Arterial Venous Fistula, Double Kidney Transplants, Is There a New Normal?, A Patient Viewpoint (changing from a catheter to a fistula), Protect Yourself and Other Patients from the Flu, and Robert Felter Award (information about PKD and information learned at the PKD annual conference). In addition, there were articles on managing conflicts, contacting the Network for help with conflict resolution and filing grievances, on-line resources of interest to renal patients, and articles about quality of life, and the flu and immunization. First person narratives described the benefits of fistula, managing conflict, and striving for independence.

2. Web Site: www.kidneypatientnews.org.

Additionally, the Network supports a Web site dedicated to information for renal patients, family members or anyone interested in renal disease: www.kidneypatientnews.org. All resources and newsletters are kept on the Web site. The site is also useful as a monitoring tool for the usefulness of the information posted. Web hits are monitored monthly to ensure that the information on the Web is being viewed. Details on Web activities are listed in Goal 4, A.2. Web Sites, on page 57.