

C. Resources & Opportunities for Beneficiaries

1. Educational Information & Activities.

To encourage independence, improve quality of life, self-care and transplantation, Network 9/10 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 2009.

- Patients participated on Network committees including the BOT, the MRB, the Grievance Committee and the Patient Leadership Committee. Throughout the year, information about the PLC 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 throughout the Network applied for the Robert Felter Memorial Award by writing about how they cope with kidney failure and how they volunteer to help others. A committee made up of Patient Leadership Committee members and Network staff reviewed 28 applications and selected one recipient for the award from Network 9 and one

from Network 10. Each recipient will attend an educational program in 2010 and share their experience with other patients.

- The Network collaborated with the Renal Support Network (RSN) to provide two patient meetings in Network 9, one in Ohio and one in Indiana. In October 2009, a meeting for patients was held near Cincinnati, Ohio with 45 people in attendance. The Network presented an overview of the Network, discussed the process for complaints and grievances, and provided information on emergency preparedness. Other topics at the meeting included transplantation, home dialysis, lifeline options, the role of the social worker, and quality of life issues. In November at the Indianapolis Patient Meeting with 94 participants, the Network presented an overview of the Network, its resources and its complaint and grievance process. Other topics at the meeting included exercise, transplantation, home dialysis stress and relationships, and motivation for a

quality of life. The Network had an information booth at both meetings where participants could obtain more information about fistula placement, rehabilitation options, quality of life, Dialysis Facility Compare, financial resources, immunizations, and technical assistance from the Network.

- The Network developed and/or updated the following resources and made them available to patients, through direct mail, the facilities, and/or on the Network Web sites: Quality of Care Concerns Handout (1567) and Poster (698), Patient Rights and Responsibilities (1567), Fistula Coaching Program Patient Coach Handbook (46), 2009 Resource Guide for Patients (12), Don't let the Bug Catch You flyer (721) and a poster on Missing Dialysis Treatment (721).

- Network resources were sent when requested and were available for download from the Network Web sites. The following are examples of resources that were sent: Access Booklets (350 sent), DPC Toolboxes (50 sent), Financial Handout Packets (48 sent), Dialysis Keeps People Alive (29 sent).

- The Network published three issues of the Renal Outreach, a

newsletter dedicated to individuals with end-stage renal disease. Approximately 6,000 copies of each edition were distributed.

The Winter 2009 edition included the following articles: a) Program Provides Transplant Patients With Lodging, b) Being Prepared for Spring Emergencies, c) Dialysis Facility Compare, d) If You Really Want to Feel Better (exercise), e) Too Much Potassium and Phosphorus, f) Do You Have a Complaint or Grievance About Your Treatment or Quality of Care, and g) The Role of The Renal Network.

The Spring 2009 edition included the following articles: a) The Robert Felter Award, b) Resources for Visual Loss, c) What to Expect After a Kidney Transplant, d) Home Dialysis – My Eighteen Years Experience, and f) The Patient Leadership Committee, g) Vocational Rehabilitation

The Fall 2009 edition included the following articles: a) The Robert Felter Memorial Award and application process, b) There's Always Something to Learn, c) My Trip to Boston, d) The Journey of Dialysis, e) ESRD Prospective Payment System, f) Commonly Prescribed Medications for Kidney Transplant Patients Part 1- Immunosuppressive Drugs, g) The Comfort of Food at a Time of Stress

and Illness, and, h) It's Flu Season Again.

- In January, the Social Worker Monthly on Visual Loss included resources to share with patients (Total 451 - 347 emailed, 104 mailed).
- In February, facilities were sent a copy of the Renal Outreach poster to post for patients to learn about the Network newsletter and how to sign up for it (643 emailed, 746 mailed).
- In March, the Social Worker Monthly on Vocational Rehabilitation included resources and articles to share with patients on going back to work and how to work from home (Total 490 - 348 emailed, 142 mailed).
- In March, information about National Kidney Month from the National Kidney Disease Education Program which described risk factors and how to talk to the family was sent to facility staff to share with patients (895 emailed).
- In March, resources about chronic kidney disease and the role of the Network were provided for a VA Hospital Health Fair.
- In April, links for advance directives information and articles for patients were provided to

social workers to share with patients (Total 483 - 350 emailed, 133 mailed).

- In June, the Social Worker Monthly contained resources and articles on support groups to share with patients (Total 490 - 358 emailed, 132 mailed).
- In July, flyers on the NKF Coffee House Conversations about Travel on Dialysis were emailed to 357 social workers to share with patients.
- In July, information from the National Kidney Disease Education Program about Making Healthy Choices for the Hot Summer Months was emailed to 296 dietitians to share with patients.
- The July Social Worker Monthly on Substance Abuse included links for patients to Alcoholic Anonymous, Narcotics Anonymous, Substance Abuse Support, and the National Resource Directory for Veterans. It was emailed to 356 social workers and mailed to 130 social workers.
- In August, information about the Patient Leadership Committee was emailed to 1,024 social workers and nurses to share with patients.

- In October, a Web link to a patient handout entitled ‘Don’t let the Bug Catch You’ was emailed to nurse manager and social workers at all facilities.
- In November, a flyer announcing a Web Ex program on the Prospective Bundling System sponsored by AAKP was emailed to 650 head nurses to share with patients.
- The November Social Worker Monthly on Anger Management included links for patients to articles on anger tips and controlling anger. It was emailed to 428 social workers and mailed to 60 social workers.
- The December Social Worker Monthly on Effective Communication Skills included links for patients to such articles as Communicating with your Health Care Team, Ask Me 3, and Stop Talking, Start Communicating. It was emailed to

428 social workers and mailed to 60 social workers.

- In December, information on staying healthy during the holiday season from the National Kidney Disease Education Program (NKDEP) was emailed to 650 head nurses and 421 social workers.
- In December, the Adherence Toolkit was mailed or emailed to all facilities (2,550). It includes the following resources for patients: Posters: a) Adequacy of Dialysis, b) Missing Dialysis: Is It Worth the Risk? and Patient Handouts: a) Compliance Article - Let’s Talk About It, b) Do You Feel As Good As You Should? c) In Control: Getting All the Dialysis You Need (vol1 n3; September 2004): A Medical Education Institute/Life Options Publication (Patient Section) and 4) Missing Dialysis: Is It Worth the Risk?

2. Web Site: Kidney Patient News (www.kidneypatientnews.org).

Network 9/10 maintains 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 useful as

a monitoring tool. Web hits and page downloads 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.