**End Stage Renal Disease Network Organization Program** 

2008
Summary Annual Report

**Centers for Medicare & Medicaid Services** 





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# Report Highlights

This section summarizes significant findings from the present report and suggests future directions for the ESRD Network Program based on these findings.

### ESRD Incidence and Dialysis Prevalence

While the number of dialysis facilities in the U.S. increased from 5,118 in 2007 to 5,408 in 2008 (Figure 2), the rate of newly occurring ESRD cases in the same time frame remained steady at 362 per million population in 2007 and 2008 (Table 3).

From 2003 to 2006, the incidence of ESRD as reported by the Networks increased steadily from year to year; however, a slower rate of change is evident for 2006 to 2008 (Figure 3). Improvements in treatment of chronic kidney disease (CKD) and other diseases that continue to put people at risk of ESRD, including diabetes and hypertension, may have had an effect on decelerating the historic rising trend in ESRD incidence. Of note, there was considerable variation in ESRD incidence across Networks in 2008, from 229 patients per million population (Network 16) to 441 per million population (Network 8).

The prevalent dialysis population increased steadily from 2003 to 2008 (Figure 4). The reasons for this may have included survival benefits from improved care for ESRD patients as well as improvements in the care of co-morbid conditions. Data released by the United States Renal Data System reveal lower mortality rates among ESRD patients across modalities and treatment duration as compared to previous years.<sup>2</sup> This lower mortality rate finding corroborates the prevalence trends highlighted in this report.

The markedly high ESRD incidence and prevalence in the African American population relative to their representation in the population as a whole (Tables 6, 10, and 22) has not been fully explained. High rates of hypertension and diabetes in this population are among the contributing factors, but more research is needed to explore whether differences in access to or quality of CKD care also contribute to relatively high ESRD rates among people identified as African American. Of note, the "Black or African American" and "American Indian or Alaska Native" categories had the smallest proportions of ESRD patients receiving transplants in 2008.

### Fistula First Breakthrough Initiative

All Networks reported an increase in AVF use among in-center and home hemodialysis patients as of December 31, 2008 (Table 19), relative to each Network's 3rd quarter 2007 baseline rate. Only 5 of the 18 Networks failed to reach their targeted goals for 2008. This

<sup>&</sup>lt;sup>1</sup> United States Renal Data System. Incidence of Reported ESRD. In: United States Renal Data System. United States Renal Data System 2008 Annual Data Report: Atlas of End-stage Renal Disease in the United States. Vol. III: Reference Tables. Bethesda, MD: National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Disease; 2009:429-452.

<sup>&</sup>lt;sup>2</sup> United States Renal Data System. Chapter 6: Mortality and Morbidity. In: United States Renal Data System. United States Renal Data System 2008 Annual Data Report: Atlas of End-stage Renal Disease in the United States. Vol. II. Bethesda, MD: National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Disease; 2009:269-280.

represents a marked improvement compared to 2007, when 16 of the 18 Networks did not meet their targeted AVF rate.

Data for all facilities participating in the Fistula First Initiative reveal that the national rate of AVF use among hemodialysis patients has improved steadily since 2002 (Figure 13); over the six-year period, the national rate increased by an average of 8.1% a year (Figure 14). Interventions implemented by the ESRD Networks have contributed to this increase. From December 31, 2007, to December 31, 2008, the national rate of AVF placement among prevalent in-center and home hemodialysis patients increased 6.4%.

### **CPM and Elab Projects**

In general, performance on the CPM measures remained essentially unchanged in 2008 relative to 2007, with a few exceptions with regard to anemia management.

Clinical performance monitoring of anemia management is likely to undergo some updates in the coming years. In 2007, the Food and Drug Administration issued a black box warning for erythropoiesis-stimulating agents after research was published suggesting a link between adverse health outcomes and hemoglobin concentrations  $\geq 13$  g/dL. Following issuance of the FDA warning, the National Kidney Foundation Kidney Disease Outcomes Quality Initiative (KDOQI) revised its anemia management guidelines and recommended a new target hemoglobin concentration for dialysis patients of 11 g/dL-12 g/dL. As a result of the black box warning and changes in the KDOQI guidelines, the percentage of dialysis patients with hemoglobin  $\geq 13$  g/dL has begun to decline and the percentage of patients with a hemoglobin concentration in the targeted range (11 g/dL-12 g/dL) is increasing. In the future, anemia management efforts are likely to focus on monitoring patients' serum hemoglobin levels to prevent them from exceeding 12 g/dL.

According to Elab data, the percentage of adult hemodialysis patients with a mean hemoglobin  $\geq 13$  g/dL was 9% in the fourth quarter of 2008, compared with 19% in 2006, the year before the black box warning was issued. For adult peritoneal patients, 14% had a mean hemoglobin  $\geq 13$  g/dL in 2008, compared with 23% in 2006. The percentage of pediatric patients with a mean hemoglobin  $\geq 13$  g/dL was 13% in 2008, compared with 17% in 2006. Nationally, 41% of all adult hemodialysis patients, 34% of adult peritoneal dialysis patients, and 29% of pediatric dialysis patients had mean hemoglobin concentrations in the 11 g/dL–12 g/dL range in the fourth quarter of 2008. This represented a 9 percentage point increase for adult hemodialysis patients relative to the fourth quarter of 2006, a 4 percentage point increase for adult peritoneal dialysis patients, and a 2 percentage point increase for pediatric dialysis patients.

CPM data show a similar trend for adult in-center HD patients. Specifically, the percentage of patients with mean hemoglobin  $\geq 11 \mathrm{g/dL}$  increased from 43% of adult in-center HD patients in the 1997 CPM study period to 82% in the 2007 CPM study period. Among adult in-center HD patients who were prescribed epoetin, 39% had a mean hemoglobin of 11.0–

<sup>&</sup>lt;sup>3</sup> Singh AK, Szczech L, Tang KL, Barnhart H, Sapp S, Wolfson M, Reddan D; CHOIR Investigators. Correction of anemia with epoetin alfa in chronic kidney disease. N Engl J Med. 2006;355(20):2085-98.

<sup>&</sup>lt;sup>4</sup> National Kidney Foundation Kidney Disease Outcomes Quality Initiative. KDOQI Clinical Practice Guideline and Clinical Practice Recommendations for Anemia in Chronic Kidney Disease: 2007 Update of Hemoglobin Target. CPG AND CPR 2.1 Hemoglobin Target. Available at: http://www.kidney.org/professionals/KDOQI/guidelines\_anemiaUP/guide1.htm

12.0 g/dL. This represents a 6 percentage point increase from the previous CPM study period.

Interestingly, the percentage of patients with mean hemoglobin  $\geq 11g/dL$  increased from 55% of adult PD patients in the 1998 CPM study period to 79% in the 2008 study period, although the 2008 finding represents a 4 percentage point decrease from 2007. Further, 65% of in-center HD pediatric patients had a mean hemoglobin  $\geq 11$  g/dL (110 g/L). This represents a 4 percentage point decrease from the previous study period. Among 731 pediatric PD patients, 65% had a mean hemoglobin  $\geq 11$  g/dL (110 g/L). This percentage represents a 6 percentage point decrease from the previous study period.

### **Vocational Rehabilitation**

The enabling federal legislation that established Medicare's ESRD Network Program in 1986 framed the program with a rehabilitation focus, not strictly as a clinical quality improvement program. The program was intended to help ensure that not only would ESRD patients be able to afford and receive good quality clinical treatment and care, but also that they would be supported in maintaining independent and fully functioning lifestyles.

There was a three-fold variation across the Networks in the reported employment rates of ESRD patients, with the highest rates (28%–29%) reported by Networks 3, 15, and 16 (Table 20). Further, there was marked variation across Networks in the rate of dialysis facilities that were open after 5:00 PM. Access to dialysis after 5:00 PM can help patients schedule treatment in ways that are flexible and enabling of other meaningful personal pursuits such maintaining employment or going to school. However, given the findings reported in Table 20, additional work is needed to understand the barriers to and facilitators of patient employment beyond the availability of dialysis treatment after 5:00 PM.

### Home Dialysis

The use of home hemodialysis is continuing to increase, up 23% from 2007 to 2008 (Table 13). The increase in home hemodialysis resulted in part from the development of home hemodialysis equipment that is more reliable, space-efficient, and user-friendly. In addition, large dialysis organizations have become more active in promoting this treatment modality. In the future, more dialysis patients are expected to select home hemodialysis as their preferred treatment modality.

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# ESRD Network Requirements and Staffing

Medicare's End Stage Renal Disease Network Organization Program (ESRD Network Program) is a national program of vital importance to individuals with irreversible kidney disease. The goal of the ESRD Network Program is to improve the quality of care for people who require dialysis or transplantation as a life-sustaining treatment. The Program is funded and managed by the Centers for Medicare & Medicaid Services (CMS).

The Social Security Act Amendments of 1972 (Public Law 92-603) extended Medicare coverage to most ESRD patients. Individuals with permanent kidney failure are eligible for Medicare if they need regular dialysis or have had a kidney transplant and they meet certain work history requirements under Social Security or the railroad retirement system, or as a federal employee. Medicare eligibility is also extended to people with permanent kidney failure if they are the spouse or child of an individual who has met specific work history criteria.

Following passage of the 1972 Amendments, in response to the need for effective coordination of ESRD care, hospitals and other health care facilities were organized into Networks to enhance the delivery of services to people with ESRD. In 1978, Public Law 95-292 modified the Social Security Act to allow for the coordination of dialysis and transplant services by linking patients, physicians, nurses, social workers, and dietitians into Network Coordinating Councils, one for each of 32 administrative areas. In 1988, CMS consolidated the 32 jurisdictions into 18 geographic areas and awarded contracts to 18 ESRD Network Organizations with responsibilities for: supporting use of the most appropriate treatment modalities to maximize quality of care and quality of life; encouraging treatment settings to support patients' vocational rehabilitation and employment; collecting, validating, and analyzing patient registry data; identifying providers that do not help achieve Network goals; and conducting onsite reviews as necessary. These ESRD Network Organizations, commonly known as ESRD Networks, serve the 50 states, the District of Columbia, and the U.S. territories of Puerto Rico, the Virgin Islands, American Samoa, Guam, and the Northern Mariana Islands (see map and Figure 1).

In 1989, Section 1881(c) of the Social Security Act was amended by PL 101-239 to provide the Networks both confidentiality in the medical review process and a limitation on liability. CMS has awarded the Networks fixed-price contracts on a three-year cycle since 1990.

CMS withholds \$0.50 from the Medicare composite rate payment for each dialysis treatment an ESRD patient receives to fund this essential program. This rate has remained the same since 1978. In 2008, the Program was funded for approximately \$26.9 million via these withholdings.

The ESRD Network Coordinating Center (NCC) supports the activities of the ESRD Networks as required by Section 1881(c) of the Social Security Act. The NCC provides centralized coordination and support for the operation of the ESRD Network Program. The NCC's primary responsibilities include collecting, maintaining, and disseminating ESRD information; coordinating national activities, including training initiatives; facilitating Special Projects as requested by CMS; and providing administrative support services.



| FIGURE 1 ESRD Network Areas |   |
|-----------------------------|---|
| Network                     | Geographic Area   |
| 1                           | CT, MA, ME, NH, RI, VT  |
| 2                           | NY  |
| 3                           | NJ, PR, VI  |
| 4                           | DE, PA  |
| 5                           | DC, MD, VA, WV  |
| 6                           | GA, NC, SC  |
| 7                           | FL  |
| 8                           | AL, MS, TN  |
| 9                           | IN, KY, OH  |
| 10                          | IL  |
| 11                          | MI, MN, ND, SD, WI  |
| 12                          | IA, KS, MO, NE  |
| 13                          | AR, LA, OK  |
| 14                          | TX  |
| 15                          | AZ, CO, NM, NV, UT, WY  |
| 16                          | AK, ID, MT, OR, WA  |
| 17                          | American Samoa, Guam, HI,<br>Northern CA, Northern<br>Mariana Islands |
| 18                          | Southern CA   |
|                             |   |

A major component of the NCC Scope of Work (SOW) is this *Summary Annual Report*. The report compiles information from the ESRD Networks' Annual Reports, as well as outcome data from two major initiatives: the ESRD Clinical Performance Measures Project and the Fistula First Breakthrough Initiative. The 18 Networks provide patient and facility data as well as descriptions of activities implemented to meet Network and CMS goals. The *Summary Annual Report* illustrates the Networks' dedication and commitment to improving the quality of life for patients with ESRD, and summarizes the Networks' role in improving outcomes for ESRD patients. This report is distributed to members of the U.S. Congress, CMS, and the ESRD Networks.

## **Network Requirements**

The ESRD Network Statement of Work (SOW) provides direction to the ESRD Network Program to ensure that each Network meets contract requirements. Network activities, as outlined in the SOW, focus on improving the quality and safety of dialysis and transplantation services provided to patients with ESRD and on promoting the independence, quality of life, and rehabilitation (to the extent possible) of patients with ESRD by supporting the use of transplantation, self-care modalities (e.g., peritoneal dialysis and home hemodialysis), and in-center hemodialysis, as medically appropriate, through the end of life.

Particular attention is given to patients' perceptions of care, to the resolution of patients' complaints and grievances, and to collaboration with facilities and providers to ensure achievement of CMS and Network goals while recognizing the intrinsic differences between types of facilities/providers (e.g., independent, hospital-based, affiliate of an organization). CMS' national goals also focus on improving the collection, reliability, timeliness, and use of data to measure processes of care and outcomes, maintain a patient registry, and support the ESRD Network Program.

As specified in the current SOW, each Network is responsible for conducting the following activities:

- Task 1: Network Quality Improvement Program: Conduct quality improvement projects that are national, local, and facility/provider-specific.
- Task 2: Community Information and Resources: Provide educational information and technical assistance to patients, dialysis facilities, and transplantation centers; additionally, this Task encompasses activities related to emergency/disaster preparedness, patient complaints/grievances, and community partnerships/coalitions.
- Task 3: Administration: Conduct Network administrative activities, including staffing and reporting, as directed by statute or by CMS.
- Task 4: Information Management: Develop information systems and administer information management for all Network activities.
- Task 5: Special Projects: Conduct Network-specific studies not currently defined under the SOW as directed or authorized by CMS.

# **Network Staffing**

CMS requires each Network, at a minimum, to employ the following staff:

- Executive Director/Project Director: Responsible for the administration of all contract requirements and overall operation of the Network. The Director has professional relationships within the ESRD community and has expertise in administration of the CMS contract, management and supervision of staff, and fiscal oversight of the Network.
- Quality Improvement Director/Quality Improvement Coordinator: Coordinates quality-related initiatives, and creates and implements the Network's quality improvement program.

- **Data Manager:** Oversees the collection, accurate recording, security, and transmission of data among facilities/providers, the Network, and CMS.
- Patient Services Coordinator: Responsible for assisting patients and their families by
  responding to questions and information requests, resolving patient or facility/provider
  complaints and grievances, and, on request, conducting training on conflict resolution and how
  to manage difficult patients. This position is full-time and performed by a person with a
  master's degree in social work or an equivalent qualification.
- Community Outreach Coordinator: Provides information and training to ESRD professionals, patients, family members, and other members of the renal community.

Additional staff in the areas of quality improvement, data, and patient services are essential for the coordination of the many Network activities; job titles vary from Network to Network.

Each Network must establish and maintain a Network Council (NC), which includes at least one patient representative and representatives from dialysis and transplantation facilities/providers located in the Network area. In addition, each Network must establish a Medical Review Board (MRB) made up of at least one patient representative and a mix of ESRD professionals—typically nephrologists, surgeons, physician assistants, nurses, social workers, dietitians—who are qualified to evaluate the quality and appropriateness of renal care. The MRB, which is advisory to the Network Council, serves as an expert panel on patient care issues. Both the NC and the MRB must meet statutory requirements with respect to composition and must adhere to strict conflict of interest guidelines.

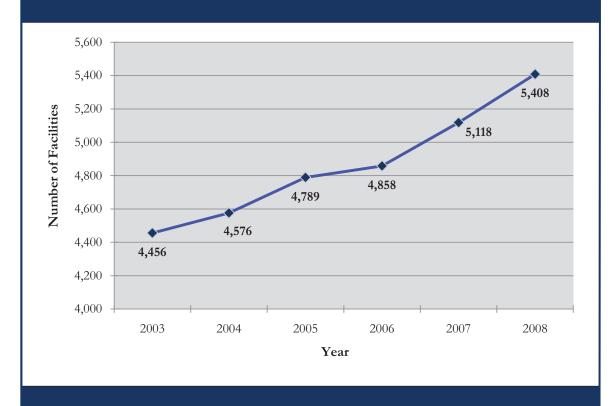
Each Network also relies on Patient Advisory Committees to provide a patient perspective that is incorporated into Network activities. Networks appoint additional standing or ad hoc committees as needed to perform their work. These committees may focus on issues such as grievances, rehabilitation, transplant, or finance. The dialysis and transplant providers in each Network area are offered opportunities to appoint representatives to Network committees. Facilities/providers are required to participate in Network activities (see Section 1881(c)(2) of the Social Security Act).

Members of these bodies are volunteers who contribute many hours of service to the Networks. The collective contribution of these members is integral to the effective functioning of the Networks and the success of the ESRD Network Programs.

Table 1 shows the number of prevalent dialysis patients, the number of dialysis facilities, and the distribution of FTEs by core contract activity for each Network in 2008. As can be seen in Figure 2, the number of dialysis facilities in the U.S. has increased steadily since 2003.

In 2008, the ESRD Networks reported a total of 196.7 full-time equivalent staff members (FTEs) to implement core CMS contract activities for renal patients who receive care at 5,408 dialysis facilities and 247 transplant centers. On average, there were 11.57 FTE staff members involved in core contract activities per Network. (The staffing totals in Table 1 do not include staff time allocated to Special Projects.) Across all Networks, the largest FTE allocation was for data management (mean = 3.34), followed by quality improvement (2.77), administration (2.39), and patient services (2.21).

FIGURE 2 Number of Dialysis Facilities as of December 31 of Each Year, 2003–2008



SOURCE OF DATA: Networks 1–18.

# **Data Management Systems**

In 1978, the Department of Health and Human Services established the Program Management and Medical Information Systems (PMMIS) as a repository of Medicare ESRD beneficiary information. This system was accessed through interactive software, the Renal Beneficiary and Utilization System (REBUS). Concurrently the 32 ESRD Network Coordinating Councils (precursors to the ESRD Networks) developed local data systems to fulfill their program requirements, including forms entry, quality assurance, and oversight functions. These Network systems had similar components, and each provided a subset of the data in the PMMIS.

In 1988, the Health Care Financing Administration, now CMS, developed ESRD Data Entry and Editing Software (EDEES) to allow electronic completion and transmittal of CMS-required ESRD forms. The Network Coordinating Councils developed utilities to merge these data into their existing systems. In 1988, the 32 ESRD Network Coordinating Councils were consolidated by Congress into 18 ESRD Network Organizations, or ESRD Networks, and the individual Network data systems were expanded to meet increased responsibilities.

In 1995, CMS and the Networks recognized the need to standardize the collection, storage, and reporting of patient registry data. The 18 Networks and CMS formed workgroups to identify best practices in the existing local data systems and established requirements for the Standard Information Management System (SIMS). Networks voluntarily tested the system and converted their existing systems to SIMS in 2000, and EDEES was eliminated. Networks continue to use SIMS to manage the ESRD dialysis and transplantation provider database and report to the central CMS repository.

CMS began development on the Vital Information System to Improve Outcomes in Nephrology (VISION) in 1999 to enable dialysis providers to enter and transmit their data electronically into SIMS. VISION was launched to all independent dialysis facilities in 2002 through the ESRD Networks, which recruited, trained, and supported local VISION users. This involved conducting workshops, preparing seed databases from SIMS, and providing phone support. After facilities submit data from VISION through the Quality Net Exchange secure data transport, Networks validate and import the data into SIMS.

In 2002, CMS replaced REBUS with the Renal Management Information System (REMIS) to provide easier access and increased functionality. Reliable linkages were built to the SIMS system, allowing data matching based on the unique patient identification number. This linkage formed the foundation for the Consolidated Renal Operations in a Web-Enabled Network (CROWN) system to connect all ESRD registry components. Other data modules within CROWN are the Fistula First Dashboard, the laboratory results database, and a Cognos-based reporting tool. The five largest dialysis organizations began providing batched electronic data directly to CMS for inclusion into CROWN in 2003. Other ESRD data resources that depend on CROWN data include the United States Renal Data System (USRDS), the Social Security Administration's Master Beneficiary Record, the United Network for Organ Sharing (UNOS), and the annual facility data reports generated by the University of Michigan Kidney Epidemiology and Cost Center.

The next evolution for the CROWN system is to combine all existing SIMS systems into a Webbased information system shared by CMS, the Networks, and facility users, with role-based access. CMS is working with several contractors and the Networks to build the CROWNWeb system, which will facilitate the collection and maintenance of information on patients and providers.



The CROWNWeb data system will support two primary CMS ESRD forms—the End Stage Renal Disease Medical Evidence Report: Medicare Entitlement and/or Patient Registration (CMS-2728) and the ESRD Death Notification (CMS-2746). The primary users of the first release of CROWNWeb will be ESRD dialysis facilities, which will use the system to add, modify, and delete information associated with these forms. Data entered by facilities in CROWNWeb will be replicated to the SIMS central repository. CROWNWeb will also require facilities to enter clinical data on all dialysis patients and report administrative information on facility personnel and dialysis services.

## Data Systems Used by ESRD Networks

All ESRD Networks rely on several data sources to fulfill their CMS contractual obligations for conducting quality improvement projects, providing technical assistance to ESRD providers and professionals, and responding to patient inquiries. These data systems are maintained and developed by CMS contractors. The following summaries briefly describe the scope and type of data available to ESRD Networks and CMS in each system.

#### **SIMS**

SIMS is a software application designed for use by the ESRD Networks to populate an ESRD patient registry that contains information documenting treatment modality and ESRD provider services. The system is used for form entry and submission tracking, and includes modules that create reports needed by the Networks. The forms that support the registry include CMS-2728 (Medical Evidence Report), CMS-2746 (Death Notification Form), CMS-2744 (Annual Facility Survey Report), and a monthly patient activity form. These forms provide data on patient demographics, patient events, and facility information including dialysis modality history. A tracking system to document patient and provider staff contacts with the Network is another module in SIMS. The database utilities provide import and export capabilities and a way to create backup files and recover the database. SIMS provides data for quality management and reporting at the national and Network levels. SIMS also supports the data collection process for the Fistula First National Quality Improvement Initiative. As of 2006, CMS no longer supported SIMS software enhancements due to priorities for development of Web-based applications for provider transmission of registry data.

In 2008, the Networks processed a total of 119,492 Medical Evidence Reports (CMS-2728) and 79,671 Death Notification Forms (CMS-2746) (Table 2).

### **ESRD Clinical Performance Measures Project**

Begun in 1993, the ESRD Clinical Performance Measures (CPM) Project is a national clinical data collection effort conducted by CMS and the 18 Networks to help providers improve patient care

and outcomes. Data are reported for samples of adult and pediatric in-center hemodialysis patients and peritoneal dialysis patients. All Veterans Health Administration in-center hemodialysis and peritoneal patients are also included. Electronic data for some elements are accepted from large dialysis organizations (LDOs). Electronically submitted data are printed onto paper forms and sent to LDO providers by the Networks to allow missing information to be entered. Independent (non-LDO) providers receive blank paper collection forms for completion. Network staff enter all data into a CMS database.

### **Electronic Laboratory Data Collection Project**

Through the Electronic Laboratory Data Collection (Elab) Project, the ESRD Network Program collects laboratory data from independent dialysis facilities and LDOs to produce facility-specific reports. The LDOs submit data electronically to a contractor, Computer Sciences Corporation (CSC). CSC then forwards the data to **Network 11** to be compiled. Independent dialysis facilities voluntarily submit patient-specific data to the Networks for data entry by Network staff. Maintaining confidentiality, the Networks send these data to Network 11. Network 11 compiles data from LDOs and independent dialysis facilities to generate facility-specific reports that are returned to the Networks for distribution to providers. This process allows for both provider-specific reports and Network trending reports for specific clinical indicators and helps Network Medical Review Boards improve patient outcomes through focused quality improvement initiatives.

#### Fistula First Initiative

In 2003, the LDOs began submitting aggregate vascular access data electronically to CMS. Independent, hospital-based, and Veterans Health Administration dialysis clinics submit their aggregate vascular access data to the Networks. The data from both sources are compiled on a monthly basis by a CMS contractor. Each Network is able to create standardized feedback reports for all providers participating in the Fistula First Initiative and mail them out on a quarterly basis. CMS produces a monthly Fistula First Outcomes Dashboard, which depicts each Network's progress in increasing arteriovenous fistula (AVF) placement rates as well as Network- and national-level data.

### **Dialysis Facility Reports**

Provider-specific data reports are generated annually based on data from Medicare dialysis hospitalization claims, Medical Evidence Reports (CMS-2728), Death Notification Forms (CMS-2746), Annual Facility Survey Reports (CMS-2744), and other CMS and Social Security Administration data sources. The University of Michigan Kidney Epidemiology and Cost Center conducts statistical analyses of the information provided in these reports with funding from CMS. The reports facilitate comparisons of patient characteristics, treatment patterns, transplantation rates, hospitalization rates, and mortality rates to local and national averages.

### United States Renal Data System

The United States Renal Data System (USRDS) is required by law to collect and analyze information about ESRD in the United States on an annual basis. USRDS collaborates with CMS, the United Network for Organ Sharing (UNOS), and the ESRD Networks by sharing datasets and actively working to improve the accuracy of ESRD patient information. The National Institute of Diabetes and Digestive and Kidney Diseases of the National Institutes of Health, with input from CMS, directs the work of the USRDS Coordinating Center, which is operated by the Minneapolis Medical Research Foundation. The USRDS Coordinating Center produces an annual data report on ESRD in the United States, fulfills data requests, provides standard analysis files and specialized datasets to

researchers, and presents the results of its research at national conferences and in peer-reviewed journals.

### United Network for Organ Sharing

The United Network for Organ Sharing (UNOS) is a nonprofit scientific and educational organization that administers the nation's only Organ Procurement and Transplantation Network (OPTN). UNOS facilitates the organ matching and placement process. UNOS also collects and manages data about every transplant event occurring in the United States and brings together medical professionals, transplant recipients, and donor families to develop organ transplantation policy.

## **Patient Characteristics**

CMS defines end stage renal disease (ESRD) as "permanent kidney failure treated with dialysis or a transplant." ESRD is the final stage on the spectrum of chronic kidney disease (CKD). An analysis of National Health and Nutrition Examination Survey data found a 30% increase in the prevalence of CKD in the U.S. from 1988–1994 to 1999–2004. This increase in CKD is partially explained by the growing number of older adults in the U.S. population as well as the increasing prevalence of diabetes, hypertension, and obesity. Although the prevalence of ESRD is related to the prevalence of CKD, not all CKD patients progress to ESRD.

According to published reports, the number of people diagnosed with ESRD increased steadily in the U.S. population from the mid-1970s through 2004. 1,4,9 Rising trends have been observed over time for both incidence (number of new patients in a given time period) and prevalence (number of existing patients at a given timepoint). Figures 3 and 4 show ESRD Network Program incidence and prevalence data for recent years. It has been predicted that the number of ESRD patients will increase to more than 700,000 by 2015. 10

The ESRD Network Program collects data on patient age, gender, race/ethnicity, primary diagnosis, and treatment modality, among other characteristics, for both incident (new) and prevalent (currently treated) ESRD patients. Data on the age and gender composition of the patient population are tracked from the Networks' Annual Reports for planning purposes. An older population may require more personal care services than a younger population, while male and female patients may have different needs for services and support and may respond to different outreach efforts. The Program collects data on patients' racial identification to allow tracking of disparities in care and outcomes.

### **Incident ESRD Patients**

Table 3 shows the number of new ESRD patients in 2008 and incident rates per million U.S. population, by Network. These incidence data come from the SIMS data system and are based on CMS-2728 forms filed for new patients in 2008.

<sup>&</sup>lt;sup>5</sup> Coresh J, Selvin E, Stevens LA, Manzi J, Kusek JW, Eggers P, et al. Prevalence of chronic kidney disease in the United States. *JAMA*. 2007;298(17):2038-2047.

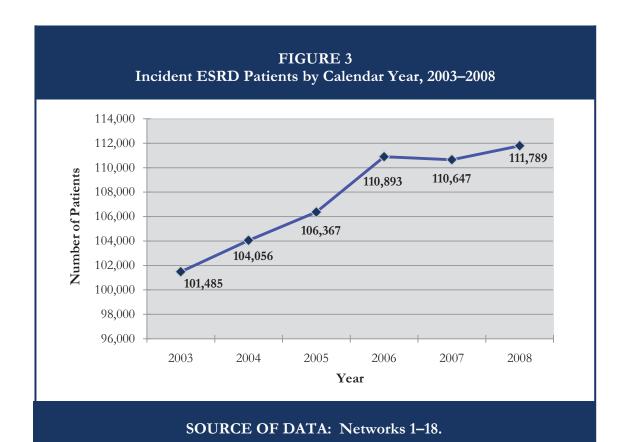
<sup>&</sup>lt;sup>6</sup> United States Renal Data System. *United States Renal Data System 2007 Annual Data Report: Atlas of End-stage Renal Disease in the United States.* Bethesda, MD: National Institute of Health, National Institute of Diabetes and Digestive and Kidney Disease; 2007.

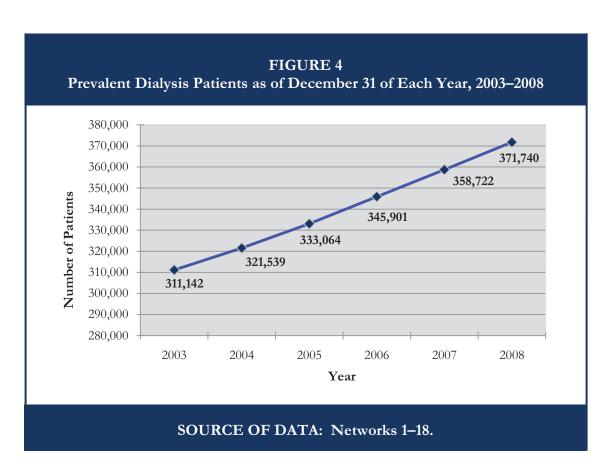
<sup>&</sup>lt;sup>7</sup> United States Renal Data System. *United States Renal Data System 2008 Annual Data Report: Atlas of End-stage Renal Disease in the United States.* Bethesda, MD: National Institute of Health, National Institute of Diabetes and Digestive and Kidney Disease; 2008.

<sup>&</sup>lt;sup>8</sup> Hsu CY, Vittinghoff E, Lin F, Shlipak MG. The incidence of end-stage renal disease is increasing faster than the prevalence of chronic renal insufficiency. *Ann Intern Med.* 2004;141(2):95-101.

<sup>&</sup>lt;sup>9</sup> Hamer RA, El Nahas AM. The burden of chronic kidney disease. BMJ. 2006;332(7541):563-564.

<sup>&</sup>lt;sup>10</sup> Gilbertson DT, Liu J, Xue JL, Louis TA, Solid CA, Ebben JP, et al. Projecting the number of patients with end-stage renal disease in the United States to the year 2015. *J Am Soc Nephrol.* 2005;16(12):3736-41. Erratum in: *J Am Soc Nephrol.* 2006;17(2):591.





Form CMS-2728 is used to register patients in the ESRD database. Dialysis facilities and transplant centers submit CMS-2728 forms to the Networks for every newly diagnosed ESRD patient; patient data are entered into SIMS by the Networks. Under an agreement with CMS, the Veterans Health Administration provides data on dialysis and transplant patients to be included in the SIMS database. Some correctional systems and military facilities voluntarily report data on maintenance dialysis patients to the Networks; these data are also included in the database.

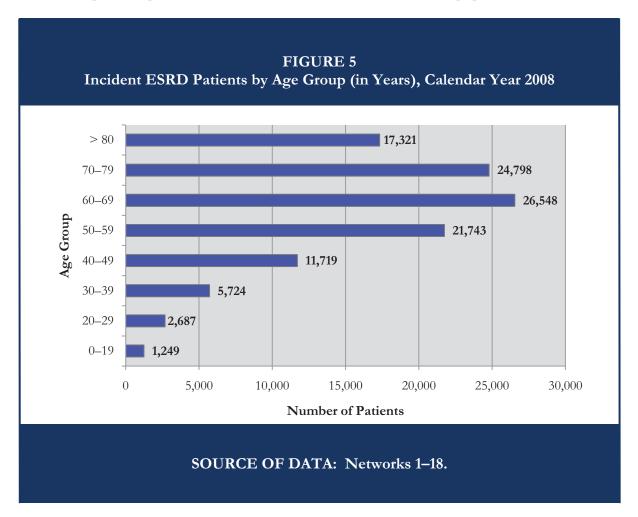
Across the country, there were 111,789 incident ESRD patients in 2008. The incidence per million population remained essentially unchanged compared to 2007 (Table 3); however, the number of incident patients increased slightly (Figure 3).

### Age

The distribution of incident ESRD patients in 2008 by age category is shown in Table 4 for the 18 Network areas and the nation as a whole. Approximately 4 out of 5 incident patients (80.9%) were 50 years of age or older, while 61.4% were 60 years of age or older (Table 4 and Figure 5). The pediatric population was small; only 1.1% of the incident ESRD patients were younger than 20 years of age in 2008. The age distribution of incident ESRD patients has remained relatively stable since 2003.

#### Gender

In 2008, males represented just over half of the incident ESRD population (56.5%; Table 5). All Networks reported a positive ratio of males to females for the incident population.

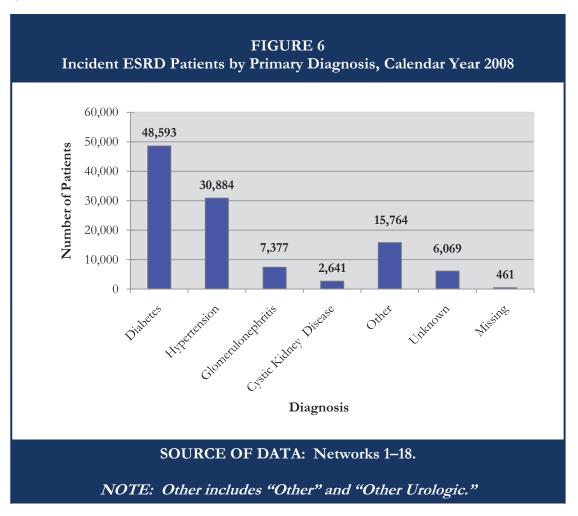


#### Race

Table 6 shows the distribution of incident ESRD patients by reported race. (Form CMS-2728 also collects data on Hispanic "ethnicity," but CMS does not currently require the Networks to report this information.) The proportion of incident patients identified as "Black or African American" was disproportionately high when compared with the representation of African Americans in the population as a whole. According to the U.S. Census Bureau, an estimated 12.9% of U.S. residents fell into the single-race "Black or African American" category in 2008, " while 27.9% of new ESRD patients in 2008 were identified as "Black or African American." Note, however, that national and Network-specific race data should be interpreted with caution because of the inherent instability in such data and because the questions used on the CMS-2728 form to elicit racial/ethnic identification differ slightly from the questions used in the 2008 Census.

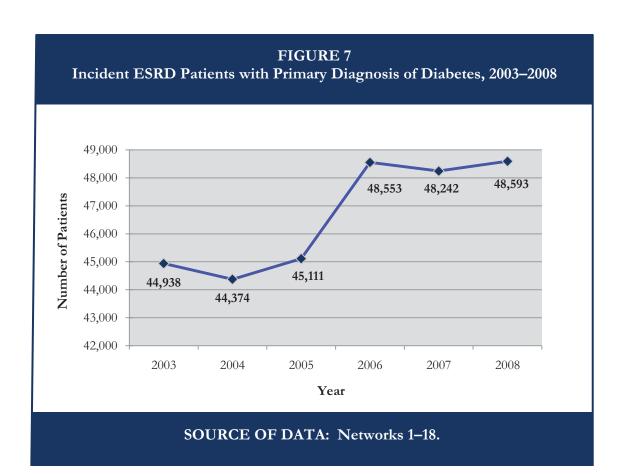
## **Primary Diagnosis**

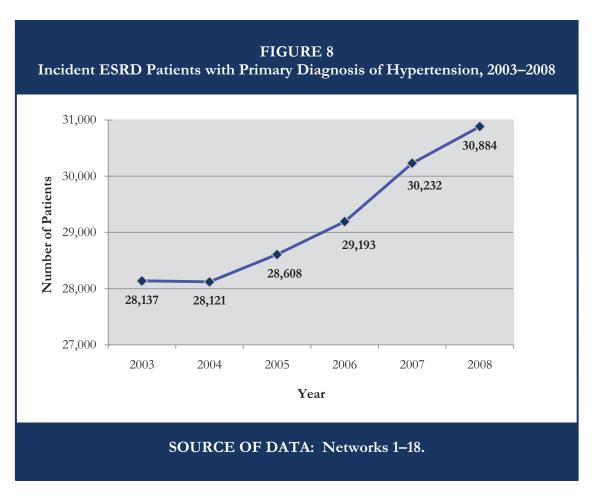
Data on primary diagnosis for incident patients comes from Form CMS-2728. The leading cause of kidney failure in incident patients was diabetes (43.5% of patients), followed by hypertension (27.6%); see Figures 6–8. Little variation existed across Networks with respect to the diagnosis leading to renal failure (Table 7).



1.1

<sup>&</sup>lt;sup>11</sup> U.S. Census Bureau. American FactFinder. Annual Population Estimates. 2008 Population Estimates. Available from: http://factfinder.census.gov





## Prevalent Dialysis Patients

At the end of every calendar year, information on prevalent patients is drawn from the SIMS database, identifying all patients who are alive and on dialysis as of December 31 of the given year. The SIMS database is updated throughout the year. Dialysis facilities and transplant centers submit Monthly Patient Activity Reports to the Networks, listing any changes in modality or provider for ESRD patients. Providers use the Death Notification Form, CMS-2746, to notify Networks of patient deaths. As changes occur, Networks update patient information in the SIMS data repository.

At the end of 2008, a national total of 371,740 patients were receiving dialysis, according to Network data (Table 1)—a 3.6% increase from 2007 (Figure 4).

### Age

Table 8 shows the age distribution of prevalent dialysis patients in 2008 for the 18 Network areas. The vast majority (77.6%) of patients were 50 years of age or older, and more than half (55.8%) were 60 years of age or older (Table 8). Only 0.6% of prevalent dialysis patients were younger than 20 years of age in 2008. The age distribution of prevalent dialysis patients has remained stable since 2003.

#### Gender

In 2008, males represented just over half of the prevalent dialysis population (55.0%; Table 9). All Networks reported a positive ratio of males to females for the prevalent dialysis population.

#### Race

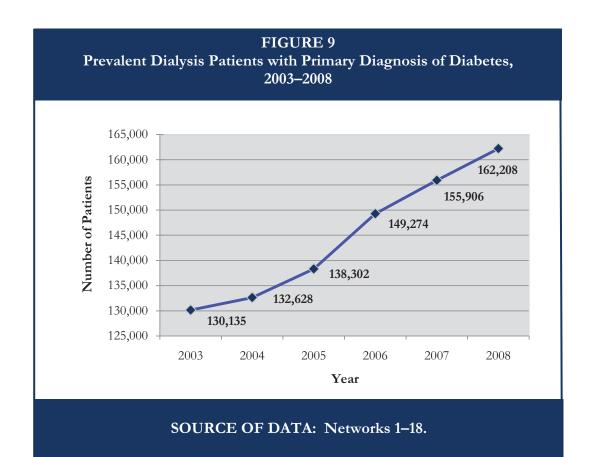
Table 10 shows the distribution of prevalent dialysis patient by reported race. (As noted above, Form CMS-2728 also collects data on Hispanic "ethnicity," but CMS does not currently require the Networks to report this information.)

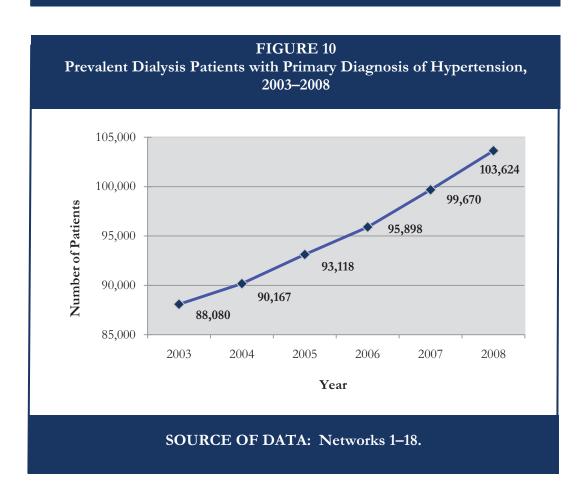
As was true for incident patients, the proportion of prevalent dialysis patients identified as "Black or African American" was disproportionately high when compared with the representation of African Americans in U.S. Census data.<sup>7</sup> Patients identified as Black/African American made up 36.9% of the total dialysis prevalent population in 2008. (As noted above, data on patients' race data should be interpreted with caution.)

### **Primary Diagnosis**

Table 11 shows the distribution of prevalent dialysis patients by primary diagnosis, for the 18 Network areas in 2008. All Networks reported diabetes as the primary cause of renal failure in 2008 for prevalent patients, as for incident patients. Overall, 43.6% of prevalent dialysis patients had a primary diagnosis of diabetes, while 27.9% had a primary diagnosis of hypertension.

Figures 9 and 10 show comparative data on the primary diagnoses of diabetes and hypertension among prevalent dialysis patients over time.





### **Treatment Modality**

ESRD patients require dialysis or transplantation to sustain life. The treatment modality depends on patient preference, patient characteristics, and provider recommendations.

Dialysis is the process of cleaning wastes from the blood using specialized equipment to take the place of the kidneys, which ordinarily perform this function. The two major forms of dialysis are hemodialysis and peritoneal dialysis. Kidney transplantation is a procedure in which the recipient receives a new kidney. The kidney can come from a family member, a nonrelated living donor, or a deceased donor.

Patients can receive life-sustaining outpatient renal replacement therapy in a range of settings. Hemodialysis can be performed "in-center" at a hospital-based facility, a corporate or independently owned dialysis facility, or a transplantation center. (Some transplantation centers provide dialysis services in addition to transplant care.) Alternatively, hemodialysis can be performed in a community setting, such as the patient's home, with a back-up facility for emergencies and periodic clinical assessment. Peritoneal dialysis is typically performed at home or work, although one form of peritoneal dialysis (Intermittent PD) is usually provided in a hospital.

In hemodialysis, blood travels through tubes to a filter, called a dialyzer, that removes wastes and extra fluid. The cleaned blood then flows through another set of tubes back into the body. In peritoneal dialysis, a dialysis solution is drained from a plastic container into the abdomen. Fluids and wastes flow through the lining of the cavity and remain "trapped" in the dialysis solution. The solution is then drained from the abdomen, removing the extra fluids and wastes from the body. There are two main types of peritoneal dialysis. The most common type is continuous ambulatory peritoneal dialysis (CAPD), which does not require a machine. The dialysis solution passes from a plastic container into the abdomen through a catheter. After several hours, the patient drains the solution into a disposable plastic container and refills the abdomen with fresh solution through the same catheter. Continuous cycling peritoneal dialysis (CCPD) uses a machine that automatically fills and drains the dialysis solution from the abdomen. A typical CCPD schedule involves several exchanges during the night while the person sleeps and one daytime exchange that lasts the entire day.

Tables 12–14 show the distribution of prevalent patients by treatment modality. In-center hemodialysis was the predominant treatment modality in 2008 (338,961 of 371,740, or 91% of prevalent patients, the same percentage as in 2007). The percentage of patients on home hemodialysis increased from 2007 to 2008 (a 23% increase), while the percentages of patients undergoing CCPD and CAPD in a self-care setting differed little from 2007 to 2008.

Table 1 shows the number of dialysis facilities in each Network area. Network 6 had the largest number of dialysis providers (547) in its geographic area, and Network 16 had the fewest facilities (147).

## Transplant Patients

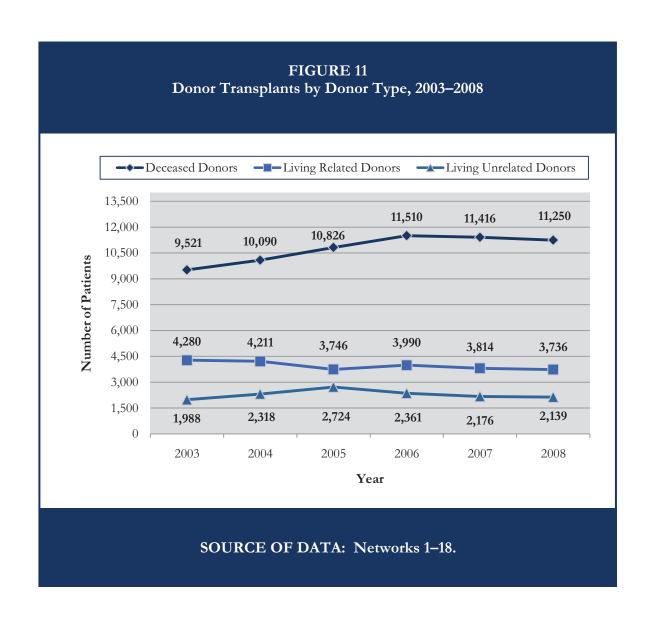
Nationwide, there were a total of 17,124 renal transplants in 2008 (Tables 15–18). The age distribution of transplant patients is shown in Table 15 by Network area and for the U.S. as a whole.

Approximately two-thirds of transplant patients were in the 40–69 age range in 2008, with the highest percentage (26.0%) in the 50–59 age category.

Data on the gender of transplant recipients are shown in Table 16. Overall, 60.9% of transplant recipients were male.

Table 17 shows the distribution of transplant recipients by race, as recorded on Form CMS-2728. The distribution was skewed relative to the racial distribution of the U.S. population as a whole, with almost a quarter of transplant recipients falling into the "Black or African American" category. Of note, ESRD Network Program data suggest that "Black or African American" and "American Indian or Alaska Native" ESRD patients were less likely to receive transplants than ESRD patients from other racial/ethnic groups (data not shown).

Table 18 shows the distribution of renal transplant patients by donor type for 2008, and Figure 11 shows comparative data for 2003–2008.



# **Quality Improvement Program**

Quality improvement activities are the centerpiece of Network efforts to improve patient care and outcomes. Specific work tasks are delineated in the Statement of Work (SOW) and support the CMS mission to ensure that the care delivered to individuals with ESRD is patient-centered, safe, effective, efficient, equitable, and timely. The SOW provides the framework for each Network to develop annually, under the direction of its Medical Review Board, a comprehensive Quality Improvement Work Plan (QIWP), which is monitored by the CMS Project Officer to evaluate the work effort, successes, and challenges associated with each quality improvement project. All QIWPs address four major quality improvement strategies:

- Improve vascular access management.
- Develop a Network project based on a Clinical Performance Measure.
- Develop a Network-specific quality improvement project.
- Conduct facility-level quality assessment and improvement activities.

All Network quality improvement activities are guided by the definition of health care quality set forth by the Institute of Medicine (IOM), which is "the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge."<sup>12</sup>

## Network-Specific Quality Improvement Projects

Throughout 2008, the Networks continued to develop quality improvement activities focused on ESRD care in their communities. In the process, the Networks established valuable partnerships and collaborations with organizations such as Quality Improvement Organizations (QIOs), State Survey Agencies, Medicare Advantage Organizations, and national and/or local renal-related professional and patient organizations, as well as with providers, patients, other Networks, and CMS as appropriate. See Figure 12 for examples of Network-level Quality Improvement Projects.

# Facility-Specific Quality Assessment and Improvement Projects

The Networks monitor, track, and distribute regional provider- and facility-specific clinical outcomes data (such as the CPM data) and, as directed or permitted by CMS, dialysis corporation—specific clinical outcomes data to identify opportunities for improving care (for example, data on vascular access, dialysis adequacy, and anemia management).

<sup>&</sup>lt;sup>12</sup> Institute of Medicine. *Crossing the Quality Chasm: The IOM Health Care Quality Initiative*. Available at: http://www.iom.edu/CMS/8089.aspx

As requested by a facility, a Network may assist in quality improvement initiatives on the facility level to help ensure that patients are receiving adequate services. These quality improvement activities typically vary from Network to Network depending on local needs and variations in patient outcomes and practice patterns. All facility-specific quality improvement projects are developed in collaboration with CMS and the Network's MRB and are approved in advance by the CMS Project Officer.

In 2008, the Networks conducted quality improvement activities using various approaches that included distributing data feedback reports; processing requests for information (for example, information on patient care, CMS Medical Evidence and Death Notification forms, and out-of-state providers for transferring patients); providing education and information for facility staff on patient resources and performance benchmarking; providing technical assistance; and assisting facilities in conducting focused local quality improvement initiatives.

| FIGURE 12<br>Examples of Network Quality Improvement Projects, 2008 |   |  |
|---|---|--|
| NETWORK 1   | Addressing Worse-than-Expected Mortality Ratios: Providers with worse-than-expected mortality ratios were identified using facility-specific data from a report generated by the University of Michigan Kidney Epidemiology and Cost Center. Network 1 staff visited the identified facilities, conducting a standardized system review with each facility's leadership. Areas of concern were recommended for Quality Assessment and Performance Improvement projects, with Network staff providing technical assistance. Mortality data will be available in 2009 to evaluate the success of this project.  |  |
| NETWORK 1   | Surgeon Vascular Access Data: Network 1 mailed profile reports to 21 high-volume vascular and general surgeons across New England. These reports, which were based on Medicare claims data for vascular access procedures, gave snapshots of the surgeons' practice patterns for 2004 and 2006, along with comparable state and Network-area data. A cover letter explained that the purpose of the report was to highlight the importance of placing AVFs and avoiding catheters. The response rate was only 21%; the responding surgeons indicated that the dataset did not reflect their practice patterns because it was limited to Medicare data. The Network also concluded based on respondent feedback that two consecutive years of data would have given a better picture of the surgeons' performance.   |  |
| NETWORK 2   | Influenza Vaccination Project: This Network 2 project was developed to improve the percentage of in-center dialysis patients who received the influenza vaccination by 5 percentage points from the 2007–2008 flu season to the 2008–2009 flu season. During the 2007–2008 flu season, 65.4% of patients received the influenza vaccine, while 79.4% of patients received the vaccine during the 2008–2009 season. The Network exceeded its goal, with an improvement rate of 14 percentage points. Network 2's activities to achieve this goal included the development of an influenza toolkit and education for patients and dialysis staff. The toolkit, which included a vaccination tracking form, was sent to each dialysis unit, along with a poster developed by CMS. Patient education was provided in various venues including regional patient meetings. Dialysis staff education was presented at Network 2's Annual Meeting. Cynthia Schulte, Public Health Program Nurse from the Bureau of Communicable Disease Control, New York State Department of Health, gave a presentation titled "Vaccination of the ESRD Patient: Improving Influenza Vaccine Coverage." |  |

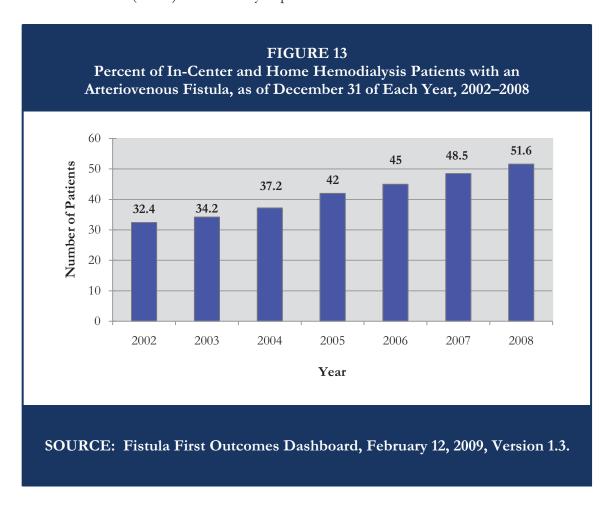
| NETWORK 3                 | Facility-Specific Intervention: Network 3 identified a set of serious infection control issues during a facility visit and began working closely with the facility to address them. Biweekly conference calls were held with the Medical Director and Administrator, and detailed monitoring was performed. Machine maintenance logs, water testing results, and patient medication records were analyzed each month, and additional training and instruction were provided as necessary. This resulted in all identified issues being resolved by the end of the year, such that 100% of required preventive maintenance procedures were being performed, 100% of water cultures were being done according to established standards, and 100% of medications were being administered according to doctors' orders.  |
|---------------------------|--|
|                           | Mini-Collaborative to Improve AVF Rates: Network 5 enlisted the participation of   |
| NETWORK 5                 | 16 facilities, all members of one large dialysis organization, in improving their AVF use rate among prevalent hemodialysis patients. These facilities served approximately 1,000 patients in West Virginia, a state that had one of the lowest AVF use rates in the nation at baseline. To effect change, the Network employed a mini-collaborative approach using the Model for Change described by Langley et al. (Langley GJ, Nolan KM, Nolan TW, Norman CL, Provost LP. The improvement guide: a practical approach to enhancing organizational performance. San Francisco: Jossey-Bass; 1996). Participating facilities improved their percent of prevalent hemodialysis patients dialyzing with an AVF from an average of 41.0% in January 2008 to an average of 44.8% in August 2008. The Network met its project goal of ≥80% of facilities meeting or exceeding Network-assigned improvement targets.  |
| NETWORK 6                 | Improving AVF Placement Rates: Network 6 conducted an intervention focused on facility-specific AVF rates. Facilities were divided into three groups based on their July 2008 AVF placement rate for prevalent hemodialysis patients. Facilities in all three groups received the Fistula First Change Package and data feedback reports that showed the facility's progress compared with other providers in the Network area. Category A facilities (AVF placement rates $\geq 50\%$ ; $n = 211$ ) were asked to describe best practices that had helped them achieve their current rate; these best practices were compiled and distributed to all Network 6 facilities. The Network did not assign specific improvement targets to facilities in this category. Category B facilities (AVF placement rates $\geq 30\%$ and $\leq 50\%$ ; $n = 261$ ) received written instructions on how to conduct root cause analyses and quality improvement interventions and were assigned facility-specific targets to be reached one year from baseline. Category C facilities (AVF placement rates $\leq 30\%$ ; $n = 37$ ) received the same written instructions plus frequent technical assistance from the Network's Medical Review Board. Category C facilities were required to complete and submit a root cause analysis and action plan. The Network worked with each of these facilities until its plan was acceptable. The Network then monitored AVF data monthly for Category C facilities, reviewed them at each MRB meeting, and provided feedback. At the one year remeasurement date, 44% of Category B facilities and 78% of Category C facilities met their goal. |
| NETWORKS 6,<br>11, AND 15 | Improving Influenza Vaccination Rates: Networks 6, 11, and 15 conducted interventions to increase influenza vaccination rates. (Network 15 also addressed rates of hepatitis B and pneumococcal pneumonia vaccinations; see below.) Using 2006–2007 facility vaccination rates, each Network selected a group of 30 of the lowest-performing facilities and randomly assigned these facilities to either a standard or intensive intervention group. All facilities received feedback reports and educational materials for patients and facility staff. The intensive group also received three Webbased seminars on immunization and quality improvement, intensive technical assistance to help them conduct root cause analyses and develop action plans, and monthly monitoring of their action plans and data. The Networks remeasured vaccination rates at the end of the project and found that, project-wide, the intensive   |

| Г                    |   |
|----------------------|---|
|                      | intervention facilities showed significantly greater improvement than the standard  |
|                      | intervention facilities.  |
| NETWORK 7            | Improving AVF Placement Rates: Network 7 used a two-pronged approach to improve fistula placement rates in Florida. Statewide interventions consisted primarily of a toolkit and educational opportunities. More intensive interventions were undertaken with a group of 35 facilities with AVF rates < 30%. Interventions for this Focus Group included regional conference calls, onsite visits, and workshops. Facilities in the Focus Group were asked to submit Quality Improvement Plans. As of the final measurement date in March 2008, the average rate of increase among Focus Group participants was greater than the average rate of increase among non-participants ( <i>p</i> < 0.0001). Lessons learned, as well as other best practices nationwide, were shared with dialysis facilities statewide.   |
| NETWORK 7            | Reducing Catheter Rates: The Network used a two-pronged approach to decreasing catheter rates in Florida. The statewide arm consisted primarily of a toolkit and educational opportunities. More intensive interventions were undertaken with a select group of underperforming facilities. Focus Group interventions included regional conference calls, onsite visits, workshops, and quarterly reporting on catheter rates. The 18 Focus Group participants began the project with a 23.1% overall rate of catheters in place for 90 days or longer. By the end of the project, the Focus Group had decreased its overall rate of catheters in place for 90 days or longer to 17.4%.   |
| NETWORKS 9<br>AND 10 | Vascular Access Coordinators: This project involved identifying a Vascular Access Coordinators in facilities that did not have one and providing them with tools, resources, and educational activities in order to improve AVF placement rates; 49 facilities participated.  |
| NETWORK 12           | Addressing Missed or Shortened Treatments: In September 2008, Network 12 initiated a project designed to improve hemodialysis adequacy by focusing on missed or shortened treatments in 8 facilities representing 560 patients. The project will continue into 2009.  |
| NETWORK 13           | Nephrologist-Specific Profiles: Network 13 targeted a group of 11 nephrologists who had more than 20 incident hemodialysis patients with no AVF placement. Physician-specific profiles were distributed, along with comparative aggregate data. Conference calls were held with most of the 11 nephrologists to discuss barriers to AVF placement for patients receiving pre-ESRD care. The identified barrier(s) became the focus for educational resources and technical assistance.  |
| NETWORK 14           | Increasing AVF Rates in Low-Performing Facilities: Network 14 worked collaborative with 14 Texas facilities in a five-county region with low AVF placement rates among prevalent hemodialysis patients. All facilities in the impacted counties had prevalent AVF rates that were less than the Network-wide rate of 48.5%, with a range of 17.6% to 47.1%, and a mean of 35.5%. In one of the identified counties, four facilities had prevalent AVF rates < 30%, the lowest prevalent AVF rates in the Network 14 area. Communications with facilities in this region verified that they experienced regional barriers to increasing prevalent AVF rates. The Network worked collaboratively with impacted facilities to present an education program, "Working Together to Improve Vascular Access Outcomes," for a target audience of 52 facility managers, nephrologists, and surgeons. Achievement of the program's primary goal, facilitating collaborative approaches to resolving AVF system barriers, was reflected in three-month post-intervention data demonstrating a 4.4 percentage point increase from baseline in the percent of prevalent hemodialysis patients using an AVF in this low-performing region. |
| NETWORK 15           | Increasing Vaccination Rates: Network 15 collected data on influenza, hepatitis B, and pneumococcal pneumonia vaccinations from facilities in the Network area. The Network developed a vaccination tracking tool, which was made available on the  |

|            | Network website. A subset of facilities worked with Network QI staff on individual                                  |  |  |
|------------|---|--|--|
|            | action plans aimed at improving their vaccination rates. Vaccination feedback reports                               |  |  |
|            | were produced and distributed to facilities in the Network area during the 2008                                     |  |  |
|            | vaccination season. Facilities working closely with Network staff had significantly                                 |  |  |
|            | higher rates of improvement than other facilities in the Network area.  |  |  |
|            | Reducing Buttonhole Technique Complications: An environmental scan  |  |  |
|            | regarding the buttonhole cannulation technique identified facilities with buttonhole                                |  |  |
|            | complications. To reduce complication rates, Network 16's QI director developed                                     |  |  |
|            | targeted resource materials for dialysis facilities:  |  |  |
| NETWORK 16 | PowerPoint presentations (with speaker's notes): "Controlling Buttonhole Infections" and "Buttonhole Complications" |  |  |
|            | Short articles: "Preparing the Vascular Access for Cannulation" and "The  |  |  |
|            | Importance of Washing Your Access"  |  |  |
|            | Handouts: "Two-Step Cleaning Protocol for Buttonhole Cannulation" and "The  |  |  |
|            | Buttonhole Technique Do's and Don'ts for Staff."  |  |  |
|            | Action plans were requested from participating facilities, and the QI Director provided                             |  |  |
|            | technical assistance. At the end of the project, the aggregate rate of buttonhole                                   |  |  |
|            | complications had decreased from 54.0% to 28.6%; complications were eliminated at                                   |  |  |
|            | 35 facilities (71%) and reduced at an additional 7 facilities.  |  |  |
|            | Fistula First Action Plans: This project was initiated in May 2008, with Network 17                                 |  |  |
|            | identifying seven facilities with the lowest prevalent AVF rates in the Network area. A                             |  |  |
|            | binder that included an Action Plan template, related articles, and Fistula First materials                         |  |  |
| NETWORK 17 | was provided to the chosen facilities. With assistance from Network 17's Fistula First                              |  |  |
|            | Subcommittee, each facility's Action Plan was reviewed quarterly. Regular feedback                                  |  |  |
|            | was provided to the facility's designated project coordinator through monthly phone                                 |  |  |
|            | and e-mail correspondence. The project continued through May 2009, with all seven                                   |  |  |
|            | participating facilities showing marked improvement in their prevalent AVF rates. As                                |  |  |
|            | of June 2009, six of the seven facilities had been able to increase their prevalent AVF                             |  |  |
|            | rates to 45% or higher.   |  |  |

# Fistula First Breakthrough Initiative

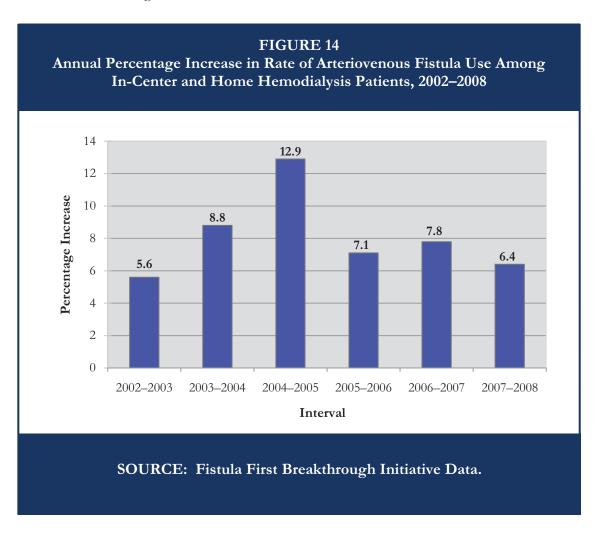
Beginning with the 2003–2006 Network Scope of Work, the Networks in partnership with CMS and renal stakeholders began a national quality improvement initiative to increase the use of arteriovenous fistulas (AVFs) in hemodialysis patients.



Hemodialysis requires repeated vascular access to large blood vessels capable of providing adequate blood flow for the effective removal of toxins from the blood. The three forms of vascular access are AVFs, arteriovenous (AV) grafts, and catheters. A patient's vasculature and other medical and physical conditions are used to determine access type. AVFs are considered the gold standard, although they are not appropriate for every hemodialysis patient. An AVF is a surgical connection between a vein and an artery, usually in the forearm. The AVF causes the vein to grow thicker, allowing the repeated needle insertions required for hemodialysis. AVFs offer greater efficiency than other forms of vascular access, with less chance of infection and clotting, because an AVF usually remains an effective means of access for many years. An AV graft created using a synthetic tube, or graft, implanted under the skin to connect an artery and a vein is an acceptable alternative when AVF placement is not possible. Catheters should be used only for temporary access while permanent access is maturing, or as permanent access in patients who have exhausted other options. Catheters pose a higher risk of infection, clotting, and narrowing of vessels than AVFs and grafts

and lead to a higher mortality rate in patients.<sup>13</sup> Patients who receive hemodialysis through an AVF have the lowest mortality; those who undergo the procedure through catheters have the highest mortality.<sup>9</sup>

The Fistula First Initiative began in 2003; at that time, according to CMS, approximately one-third (34.2%) of all prevalent in-center and home hemodialysis patients in the United States were undergoing dialysis with a fistula. In 2005, the Fistula First Initiative was designated the first CMS ESRD "Breakthrough Initiative," with a five-year national goal of at least 66% fistula use in prevalent dialysis patients by June 30, 2009. Each Network is required to demonstrate an annual 20% decrease in its AVF quality deficit. The quality deficit is the difference between the Network's AVF rate and the CMS goal of 66%.



As shown in Table 19, all Networks reported an increase in AVF use among in-center and home hemodialysis patients as of December 31, 2008, relative to each Network's 3rd quarter 2007 baseline rate. Only 5 of the 18 Networks failed to reach their targeted goals for 2008. This represents a

<sup>&</sup>lt;sup>13</sup> Reddan D, Klassen P, Frankenfield DL, Szczech L, Schwab S, Coladonato J, et al.; National ESRD CPM Work Group. National profile of practice patterns for hemodialysis vascular access in the United States." *J Am Soc Nephrol.* 2002;13(8):2117-24.

marked improvement compared to 2007, when 16 of the 18 Networks did not meet their targeted AVF rate.

Data for all facilities participating in the Fistula First Initiative reveal that the national rate of AVF use among hemodialysis patients has improved steadily since 2002 (Figure 13); over the six-year period, the national rate increased by an average of 8.1% a year (Figure 14). Interventions implemented by the ESRD Networks have contributed to this increase. From December 31, 2007, to December 31, 2008, the national rate of AVF placement among prevalent in-center and home hemodialysis patients increased 6.4%.

## Fistula First Quality Improvement Projects

As part of the Network's QIWP, each Network defines the opportunity for improvement in the area of vascular access and develops both outcome and process indicators, prepares a project design and methodology that support statistical analysis, proposes intervention activities, and specifies an evaluation mechanism.



## Fistula First Outreach, Education, and Technical Assistance

All ESRD Networks are tasked with improving AVF placement rates as part of the Fistula First initiative. The Networks use a variety of approaches in working with patients, facilities, and practitioners to increase AVF placement rates, including:

- Developing posters, brochures, and other vascular access educational materials targeting patients, dialysis facility staff, or both
- Posting Network-developed posters, brochures, and other educational materials tools on the Network's website
- Posting national Fistula First information and tools on the Network's website
- Posting data on AVF placement rates on the Network's website
- Offering presentations on vascular access issues at patient meetings
- Sponsoring workshops for dialysis facility staff, including nurses and patient care technicians
- Providing training for facility staff through live WebEx presentations that are subsequently made available on the Network's website
- Conducting onsite training for dialysis facility staff

- Sponsoring or co-sponsoring workshops for physicians, including vascular surgeons and nephrologists
- Offering presentations at professional meetings sponsored by other organizations
- Publishing articles on vascular access in the Network's patient and professional newsletters
- Publishing Fistula First newsletters for distribution to dialysis facilities
- Contributing articles to other renal organizations' newsletters
- Providing national, state-level, facility-specific, and county-level data and other relevant information to dialysis facilities through quarterly Fistula First feedback reports
- Providing data on individual physicians' vascular access patterns to dialysis facilities and physician offices
- Encouraging facilities to designate one staff member to serve as the point person for vascular access issues
- Encouraging facilities to develop protocols for cannulating new fistulas
- Using awards and other forms of recognition to spotlight facilities with high AFV rates and those showing the most improvement within specified timeframes
- Working closely with low-performing facilities as part of focused Quality Improvement Projects
- Offering onsite technical assistance to dialysis facility staff.

Specific examples of the Networks' Fistula First outreach, education, and technical assistance activities are shown on pages 56–60 of this report (Networks 4, 5, 9/10, and 16).



# ESRD Clinical Performance Measures Project

The ESRD Clinical Performance Measures (CPM) Project is a national effort led by CMS and the 18 ESRD Networks to help dialysis providers improve patient care and outcomes.

Section 45558 of the Balanced Budget Act of 1997 required the Secretary of Health and Human Services to develop and implement a method for measuring and reporting the quality of renal dialysis services provided to Medicare beneficiaries. Sixteen Clinical Performance Measures (CPMs) were developed, based on the National Kidney Foundation Kidney Disease Outcomes Quality Initiative (NKF KDOQI) Practice Guidelines. The CPM Project provides important information to CMS and the Networks on outcome measures at both the national and Network levels. CPM data serve as the foundation for many of the Networks' quality improvement activities.

CMS has identified four areas of care as the focus of the CPM Project:

- Adequacy of dialysis, as measured by the urea reduction ratio (URR) and single-pool Kt/V (spKt/V) for hemodialysis patients, and weekly Kt/V<sub>urea</sub> and creatinine clearance for peritoneal dialysis patients. These measurements are used to determine whether the dialysis dosage is adequate. The URR is a method of comparing pre- and post-dialysis levels of blood urea nitrogen (a waste product removed by dialysis). Urea is normally removed from the blood by the kidneys and then excreted in the urine; in people with renal failure, urea accumulates in the body. The reduction in urea as a result of dialysis, or the URR, is one measure of how effectively a dialysis treatment removed waste products from the body. Kt/V is a ratio used to determine the effectiveness of a dialysis treatment. Kt equals clearance multiplied by time, representing the volume of fluid completely cleared of urea during a single treatment. V represents the volume of water a patient's body contains. For hemodialysis patients, spKt/V is the most commonly used method of measuring urea clearance, while Kt/V<sub>urea</sub> is used in peritoneal dialysis patients. Creatinine clearance is a measure of kidney function.
- Vascular access (for in-center hemodialysis patients), defined as use of an arteriovenous fistula (AVF), arteriovenous (AV) graft, or catheter.
- Anemia management, as indicated by hemoglobin concentration, transferrin saturation, and serum ferritin concentration. Virtually all patients with chronic kidney disease develop anemia due to decreased production of erythropoietin by the kidneys. Erythropoietin is a hormone produced by normal kidneys that stimulates the bone marrow to make an adequate number of red blood cells, assuring oxygen delivery to the tissues. With increasing damage to the kidneys, the production of erythropoietin decreases, so the bone marrow produces fewer red blood cells and anemia develops. The most commonly used test to diagnose anemia is the level, or concentration, of hemoglobin in the blood. Transferrin saturation and serum ferritin are methods of testing iron deficiency. The transferrin saturation test indicates how much iron is available to make red blood cells. The serum ferritin test shows the level of iron in the liver, indicating the amount of iron stored in the body.

<sup>&</sup>lt;sup>14</sup> The National Kidney Foundation. National Kidney Foundation Kidney Disease Outcomes Quality Initiative (NKF K/DOQI<sup>TM</sup>). Available at: http://www.kidney.org/professionals/kdoqi/index.cfm

• Nutritional status, as indicated by serum albumin concentration measured using one of two laboratory methods: bromcresol green (BCG) or bromcresol purple (BCP). Albumin is a protein found in blood plasma. Serum albumin concentration is a widely used measure of nutritional status in maintenance dialysis patients.

The CPM Project's Annual Report for 2008<sup>15</sup> includes data for the 2008 study period. For in-center hemodialysis patients, the study period was October–December (4<sup>th</sup> quarter) 2007. For peritoneal dialysis patients, the study period included October–December (4<sup>th</sup> quarter) 2007 and January–March (1<sup>st</sup> quarter) 2008. The Annual Report compares the 2007 study period findings with findings from previous study periods and identifies opportunities to improve care for dialysis patients.

The 2008 CPM Report notes that, although major improvements have occurred in the care of dialysis patients in the United States, further improvements are needed in the areas of adequacy of dialysis, vascular access, and anemia management.

## **Sampling Procedures**

The CPM Project collects data for the following groups and time periods:

- A national sample of adult in-center hemodialysis patients (October–December 2007)
- A national sample of adult peritoneal dialysis patients (October 2007–March 2008)
- A national sample of pediatric (aged <18 years) in-center hemodialysis patients (October–December 2007)
- A national sample of pediatric (aged <18 years) peritoneal dialysis patients (October 2007– March 2008).

In April 2008, a census of adult (aged ≥ 18 years as of September 30, 2007) in-center hemodialysis and peritoneal dialysis patients who were alive and dialyzing on December 31, 2007, was obtained from each of the 18 ESRD Networks. The CPM analytic samples of adult in-center hemodialysis patients and peritoneal dialysis patients were drawn from this universe of patients.

The CPM Project also collected information on in-center hemodialysis and peritoneal dialysis patients aged < 18 years for the four core indicators of dialysis care (dialysis adequacy, vascular access for hemodialysis patients, anemia management, and nutritional status) although no CPMs have been established for the pediatric age group.

Since 2001, the Networks have been required by CMS contract to collect CPM information on a 100% sample of in-center hemodialysis and peritoneal dialysis patients from all Veterans Health Administration (VHA) dialysis providers. These data are compiled by CMS into an annual report

<sup>&</sup>lt;sup>15</sup> Centers for Medicare & Medicaid Services. 2008 Annual Report: ESRD Clinical Performance Measures Project: Opportunities to Improve Care for In-Center Hemodialysis and Peritoneal Dialysis Patients. Baltimore, MD: CMS; 2008. Available at: http://www.esrdnetwork.org/assets/pdf/data/2008cpmannualreport.pdf

that provides demographic profiles and CPM results at the provider and national VHA levels and allows comparison to the Medicare CPM results. VHA data are not included in the CPM Project Annual Report.

### Adult In-Center Hemodialysis Sample

A random sample of adult in-center hemodialysis patients was drawn from each Network's patient census. The sample size for each Network was selected to allow for 95% confidence intervals (CI) no larger than 10 percentage points (i.e.,  $\pm$  5%) for Network-specific estimates of the key hemodialysis CPMs and other indicators. Additionally, a 30% oversample was drawn from each Network using the same random selection process as for the larger sample. Oversampling was employed to compensate for the anticipated non-response rate and to assure a large enough number of patients dialyzing at least six months prior to October 1, 2007, as required for certain CPM analyses.

The national stratified random sample consisted of 8,926 adult in-center hemodialysis patients. Of these patients, 8,730 met the criterion for inclusion in data analyses; patients were included if they had at least one paired set of pre- and post-dialysis BUN values, one hemoglobin value, and one serum albumin value within the three-month study period.

A weighting factor was assigned to each patient in the analytic sample based on the proportion of each ESRD Network area's total population sampled.

### Adult Peritoneal Dialysis Sample

A random sample of 5% of adult peritoneal dialysis patients was drawn from the national census of adult hemodialysis and peritoneal dialysis patients. To compensate for the anticipated non-response rate, a 10% oversample was drawn using the same random selection process as for the 5% sample. Again, the national peritoneal dialysis sample included some prisoners, but no VA patients.

The 5% random sample consisted of 1,497 adult peritoneal dialysis patients. Of these patients, 1,472 met the criteria for inclusion in data analyses: patients were included if they had at least one hemoglobin and one serum albumin value available within the six-month period.

### Pediatric In-Center Hemodialysis Sample

Of 740 pediatric (aged < 18 years) in-center hemodialysis patients in the U.S. who were reported to be on dialysis as of December 31, 2007, 693 were included in the sample for analysis. Patients were included in the sample if they had at least one paired set of pre- and post-dialysis BUN values, one hemoglobin value, and one serum albumin value for the three-month study period.

#### **Pediatric Peritoneal Dialysis Sample**

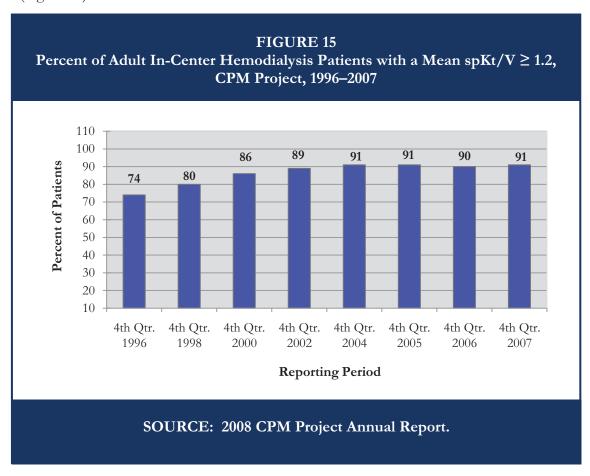
Of 753 pediatric peritoneal dialysis patients in the U.S. who were reported to be on dialysis who were reported to be on dialysis as of December 31, 2007, 731 were included in data analyses. The criteria for inclusion were: receiving peritoneal dialysis at any point during the six-month study period and having at least one hemoglobin and one serum albumin value available for the six-month period.

## Key Findings for the Adult In-Center Hemodialysis Sample (n = 8,730)

As noted above, the following findings for the adult in-center hemodialysis (HD) sample were calculated using weighted data.

### **HD** Adequacy

- 89% of patients in the adult in-center HD sample met the HD adequacy threshold of a mean  $URR \ge 65\%$ .
- The overall mean  $\pm$  standard deviation (SD) URR was 72.4  $\pm$  6.3%.
- 91% of patients in the sample met the HD adequacy threshold of a mean spKt/V  $\geq$  1.2 (Figure 15).

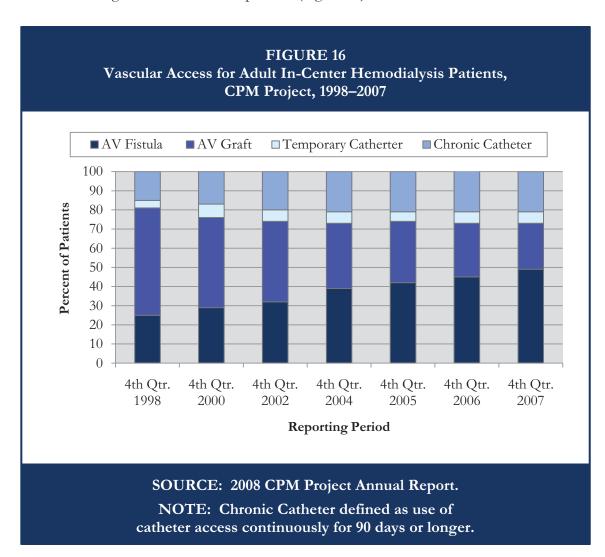


- 95% of female patients and 89% of male patients were receiving dialysis with a mean  $spKt/V \ge 1.2$ .
- 94% of patients on dialysis for six months or more and dialyzing three times a week (n = 7,505) had a mean delivered spKt/V  $\geq 1.2$  calculated using the Daugirdas II formula.
- The overall mean  $\pm$  SD spKt/V was 1.56  $\pm$  0.27.

- The mean  $\pm$  SD dialysis session length was 218  $\pm$  34 minutes.
- HD adequacy as indicated by a mean delivered spKt/V  $\geq$  1.2 has improved over time, from 74% of HD patients the in 4th quarter of 1996 to 91% in the 4th quarter of 2008 (Figure 15).

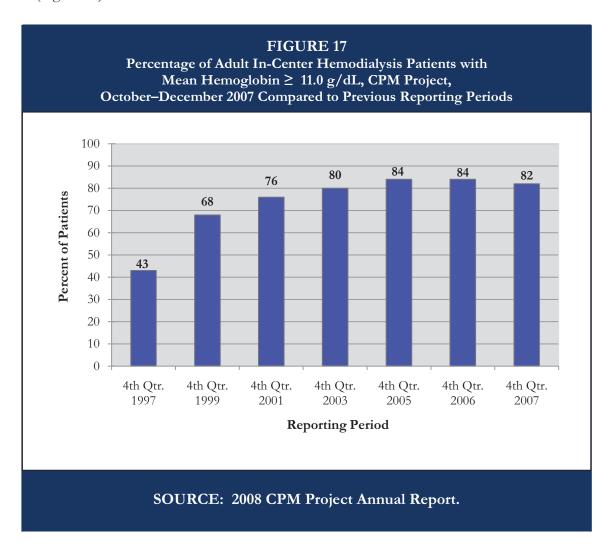
#### Vascular Access

- According to CPM data, 49% of prevalent adult in-center HD patients were undergoing dialysis via an AVF at their last HD session during the study period, an increase from 45% in 2006.
- Among adult in-center HD patients who were dialyzed with an AFV or an AV graft at their last dialysis session during the study period, 72% had their access routinely monitored for the presence of stenosis during the study period.
- The CPM Project has recorded steady annual increases in AVF use since 1998, when the rate was 26% among adult in-center HD patients (Figure 16).



### Anemia Management

• The percentage of patients with mean hemoglobin ≥ 11g/dL increased from 43% of adult incenter HD patients in the 1997 CPM study period to 82% in the 2007 CPM study period (Figure 17).



- Among adult in-center HD patients who were prescribed epoetin, 39% had a mean hemoglobin of 11.0–12.0 g/dL. This represents a 6 percentage point increase from the previous CPM study period.
- Among adult in-center HD patients who had a first monthly hemoglobin < 11 g/dL for at least one of the study months and/or who were prescribed epoetin at any time during the study period, 97% had at least one documented transferrin saturation value and one documented serum ferritin concentration value during the three-month study period.
- Among patients who had a first monthly hemoglobin < 11 g/dL for at least one of the study months or who were prescribed epoetin at any time during the study period, 84% had at least

one transferrin saturation  $\geq 20\%$  and one serum ferritin concentration  $\geq 100$  ng/mL during the study period.

• Among patients who met the inclusion criteria for the "Administration of Supplemental Iron" CPM, 83% were prescribed intravenous iron in at least one month during the study period.

#### Serum Albumin

- The CPM Project uses two sets of criteria to assess whether serum albumin levels are adequate. The first, broader, set of criteria uses thresholds of ≥ 3.5 g/dL (BCG method) and ≥ 3.2 g/dL (BCP method) to define adequate serum albumin. The second, narrower, set of criteria defines adequate nutritional status using thresholds of ≥ 4.0 g/dL (BCG) and ≥ 3.7 g/dL (BCP).
- During the three-month study period, 82% of patients in the adult in-center HD sample met the broad threshold for adequate serum albumin, with a mean value ≥ 3.5 g/dL (BCG) or ≥ 3.2 g/dL (BCP).
- 34% of patients met the narrow threshold for adequate serum albumin, as indicated by a mean value  $\geq$  4.0 g/dL (BCG) or  $\geq$  3.7 g/dL (BCP) for the three-month study period.
- The overall mean  $\pm$  SD serum albumin values were 3.8  $\pm$  0.4 g/dL (BCG) and  $\geq$  3.5  $\pm$  0.5 g/dL (BCP).

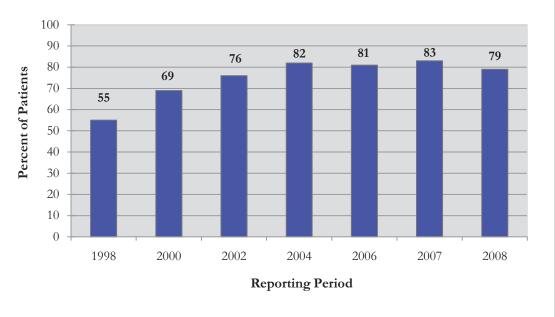
## Key Findings for the Adult Peritoneal Dialysis Sample (n = 1,472)

#### Peritoneal Dialysis (PD) Adequacy

For all patients in the adult PD sample, excluding tidal dialysis patients (n = 71):

- 87% had at least one measured total solute clearance for urea and one measured creatinine during the six-month study period.
- The mean weekly Kt/ $V_{urea}$  for CAPD patients in the sample was 2.22  $\pm$  0.67.
- 84% had a mean weekly  $Kt/V_{urea} \ge 1.7$ .
- $\bullet$  The mean weekly Kt/V  $_{\rm urea}$  for cycler patients was 2.25  $\pm$  0.66.
- 72% of CAPD patients had a mean weekly  $Kt/V_{urea} \ge 2.0$  and a mean weekly creatinine clearance  $\ge 60L/\text{week}/1.73\text{m}^2$  or there was evidence the dialysis prescription was changed if the adequacy measurements were below these thresholds during the six-month study period.
- 65% of cycler patients had a mean weekly  $Kt/V_{urea} \ge 2.1$  and a mean weekly creatinine clearance  $\ge 63 \text{ L/week/1.73m}^2$  or there was evidence the dialysis prescription was changed if the adequacy measurements were below these thresholds during the six-month study period.





SOURCE: 2008 CPM Project Annual Report.
NOTE: The 2008 reporting period was October 1, 2007, to March 31, 2008.

### Anemia Management

- The percentage of patients with mean hemoglobin ≥ 11g/dL increased from 55% of adult PD patients in the 1998 CPM study period to 79% in the 2008 study period; the 2008 finding represents a 4 percentage point decrease from 2007 (Figure 18).
- Among adult PD patients who were prescribed epoetin, 42% had a mean hemoglobin of 11.0–12.0 g/dL. This represents a 5 percentage point increase from the previous study period.
- Among adult PD patients who had a first monthly hemoglobin < 11 g/dL for at least one of the study months or who were prescribed epoetin at any time during the study period, 86% had at least two documented transferrin saturation values and two documented serum ferritin concentration values during the six-month study period. This represents a 12 percentage point increase from the 2007 study period.
- Among adult PD patients who had a first monthly hemoglobin < 11 g/dL for at least one of the study months or who were prescribed epoetin at any time during the study period, 89% had at least one transferrin saturation ≥ 20% and one serum ferritin concentration ≥ 100 ng/mL during the study period.

• Among adult PD patients who met the inclusion criteria for the "Administration of Supplemental Iron" CPM, 39% were prescribed intravenous iron in at least one of the two-month periods during the study period.

#### Serum Albumin

- 62% of patients in the adult PD sample had a mean serum albumin ≥ 3.5 g/dL (BCG) or ≥ 3.2 g/dL (BCP) for the six-month study period.
- 19% of patients had a mean serum albumin ≥ 4.0 g/dL (BCG) or ≥ 3.7 g/dL (BCP) for the six-month study period.
- The overall mean  $\pm$  SD serum albumin values were 3.6  $\pm$  0.5 g/dL (BCG) and 3.3  $\pm$  0.6 g/dL (BCP).

## Key Findings for the Pediatric In-Center HD Sample (n = 693)

### **HD** Adequacy

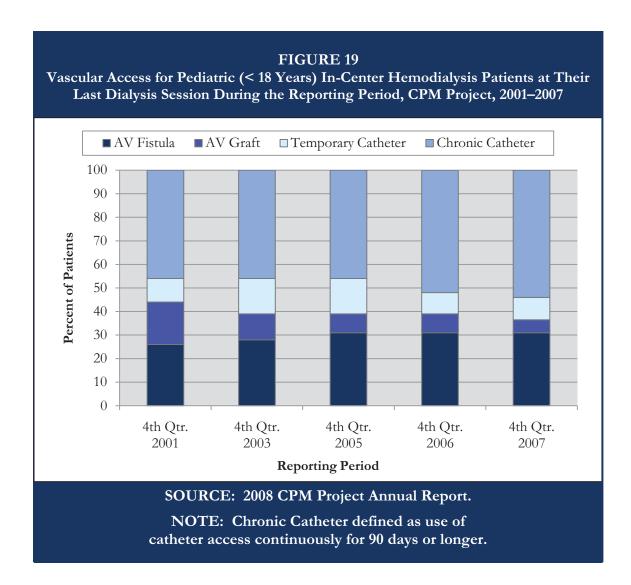
- 90% of pediatric in-center HD patients had a mean spKt/V ≥ 1.2 calculated using the Daugirdas II formula.
- The overall mean  $\pm$  SD spKt/V was 1.59  $\pm$  0.32.

#### Vascular Access

- 31% of pediatric in-center HD patients were dialyzed with an AVF (Figure 19).
- Among pediatric in-center HD patients who were dialyzed with an AVF or an AV graft at their last dialysis session during the study period, 57% had their access routinely monitored for the presence of stenosis. This represents a 7 percentage point decrease from the previous study period.
- 54% of patients in the pediatric in-center HD sample were dialyzed with a catheter continuously for 90 days or longer (Figure 19).

### Anemia Management

- 65% of pediatric in-center HD patients had a mean hemoglobin ≥ 11 g/dL (110 g/L). This represents a 4 percentage point decrease from the previous study period.
- The overall mean  $\pm$  SD hemoglobin was 11.3  $\pm$  1.5 g/dL (113  $\pm$  15 g/L).
- 80% of patients had a mean transferrin saturation  $\geq$  20%.
- 83% of patients had a mean serum ferritin concentration  $\geq 100 \text{ ng/mL}$ .
- 17% of patients had a mean serum ferritin > 800 ng/mL.



Serum Albumin

- 86% of patients in the pediatric in-center HD sample had a mean serum albumin  $\geq$  3.5 g/dL (BCG) or  $\geq$  3.2 g/dL (BCP) for the three-month study period.
- 54% of patients had a mean serum albumin  $\geq$  4.0 g/dL (BCG) or  $\geq$  3.7 g/dL (BCP) for the three-month study period.
- The overall mean  $\pm$  SD serum albumin values were 3.9  $\pm$  0.5 (BCG) and 3.6  $\pm$  0.6 g/dL (BCP).

# Key Findings for the Pediatric PD Sample (n = 731)

#### **PD** Adequacy

• 82% of pediatric PD patients had a mean weekly  $Kt/V_{urea} \ge 1.8$ .

- The mean weekly Kt/V<sub>urea</sub> for CAPD patients in the pediatric PD sample was  $2.47 \pm 0.81$ .
- $\bullet$  The mean weekly Kt/V  $_{urea}$  for cycler patients was 2.40  $\pm$  0.78.

### Anemia Management

- 65% of patients had a mean hemoglobin ≥ 11 g/dL (110 g/L). This percentage represents a 6 percentage point decrease from the previous study period.
- Mean  $\pm$  SD hemoglobin was 11.4  $\pm$  1.4 g/dL (114  $\pm$  14 g/L).
- 80% of patients had a mean transferrin saturation  $\geq$  20%.
- 74% of patients had a mean serum ferritin concentration  $\geq$  100 ng/mL.
- 7% of patients had a mean serum ferritin concentration  $\geq 800 \text{ ng/mL}$ .

#### Serum Albumin

- 68% of patients in the pediatric PD sample had a mean serum albumin  $\geq$  3.5 g/dL (BCG) or  $\geq$  3.2 g/dL (BCP) for the six-month study period.
- 32% of patients had a mean serum albumin  $\geq$  4.0 g/dL (BCG) or  $\geq$  3.7 g/dL (BCP) for the six-month study period.
- The overall mean  $\pm$  SD serum albumin values were 3.7  $\pm$  0.6 g/dL (BCG) and 3.4  $\pm$  0.6 g/dL (BCP).

**Note:** The 2008 SAR will be the last report to provide an ESRD Clinical Performance Measures Project section. Beginning with the 2009 SAR, national data that summarize the quality of renal care will be provided by the Electronic Laboratory Data Collection (Elab) Project that is implemented by Network 11.

# Electronic Laboratory Data Collection (Elab) Project

Through the Elab Project, the ESRD Network Program collects data electronically from independent dialysis facilities and large dialysis organizations (LDOs) across the 18 Network areas. Electronic data collection eliminates the time-consuming and resource-intensive work of manually collecting laboratory data on a large scale; reduces transcription errors; and improves the accuracy, timeliness, comparability, consistency, and reliability of Network-level and national data.

Elab Project data are used to generate facility-specific reports that include data at the facility, state, and Network levels. These reports can be used to identify facilities that would benefit from Network quality improvement interventions, including technical assistance, help with strategic planning, or on-site clinical assessments. A facility's progress toward a specific goal can be tracked with these reports, making them useful tools for quality improvement projects. The Networks can also use these reports to identify best-practice facilities so their experiences can be shared with other facilities in the Network area.

The Elab Project began in 1998 with **Network 11** receiving ESRD data directly from laboratories, with the consent of dialysis facilities, and using these data to generate facility-specific reports. The Project was later expanded to include additional test Networks, and in 2003 was offered to all of the Networks. Subsequently, CMS determined that the Clinical Laboratory Improvement Amendments (CLIA) restrict laboratory results from going directly to a third party, so the flow of data changed. In 2004, data were available for 14 Network areas, and by 2007, data were again available for all 18 Network areas (Figure 20). In 2008, Network 11 was awarded a contract by CMS to generate facility-specific and national reports using data from all 18 Networks. The first national Elab Project report was published by Network 11 using 2008 data.<sup>16</sup>

Since 2002, Network 11 has collaborated with CMS and Computer Sciences Corporation (CSC) to coordinate lab data on hemodialysis and peritoneal dialysis patients for the Elab Project. Data for each year cover the three-month period from October 1 to December 31. The LDOs submit data electronically to CSC. CSC then formats the information according to Network 11 specifications and forwards it to Network 11. Each Network collects data from its independent dialysis facilities and, using CMS-approved security measures, submits the data along with patient demographic information to Network 11. Network 11's biostatistician then merges the data from LDOs and independent dialysis facilities to produce dialysis facility—specific reports, which are provided to the Networks. All reports include data that allow each dialysis facility to compare its own results to state- and Network-level results for the same time period for each quality indicator.

Laboratory measures collected for hemodialysis patients include:

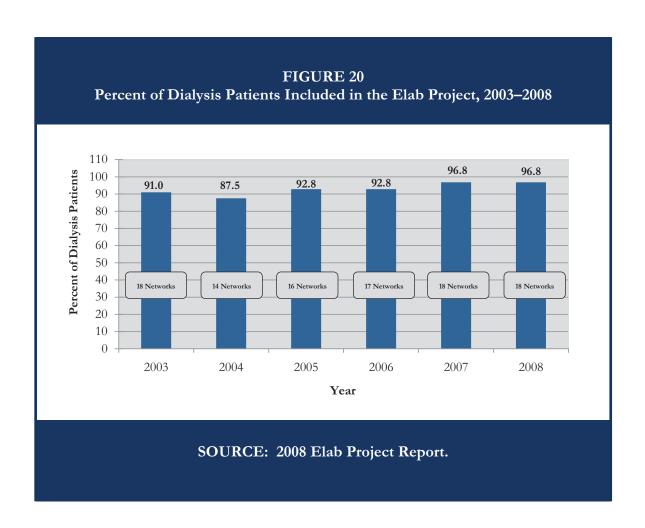
- Pre-dialysis hemoglobin concentration
- Pre-dialysis serum ferritin concentration
- Pre-dialysis percent transferrin (iron) saturation (TSAT)

<sup>&</sup>lt;sup>16</sup> Renal Network of the Upper Midwest, Inc. *Elab Project: National 2008 and Trends Report, June 2009.* St. Paul, MN: Renal Network of the Upper Midwest; 2009.

- Pre- and post-dialysis blood urea nitrogen (BUN) concentration, used to calculate urea reduction ratio (URR)
- URR
- Single-pool Kt/V (spKt/V)
- Pre-dialysis serum albumin concentration
- Pre-dialysis serum phosphorus concentration
- Pre-dialysis serum calcium concentration.

Laboratory measures collected for peritoneal dialysis patients include:

- Hemoglobin concentration
- Serum ferritin concentration
- Percent transferrin (iron) saturation (TSAT)
- Weekly Kt/V<sub>urea</sub> (dialysate and urine clearance)
- Weekly creatinine clearance
- Serum albumin concentration
- Serum phosphorus concentration
- Serum calcium concentration.



Facilities were asked to submit the first lab value of the month for each measure for October, November, and December of each year. A patient was included for analysis if at least one monthly lab value for that measure was submitted. For each patient, the mean value for the three-month period was determined. URR results < 10% or > 90% and any associated Kt/V results were excluded from the calculations.

All 18 ESRD Networks participated in the 2008 data collection for the Elab Project. The final database included data for 5,164 dialysis facilities and more than 355,000 dialysis patients. Overall, data were received for 96.8% of the dialysis patient population in the U.S., with Network percentages ranging from 93% to 99%. Figure 20 shows the percent of dialysis patients for whom data were received, by Network, from 2003 to 2008.

## Elab Project Data: 2008 Highlights

The following highlights reflect clinical data from 328,016 adult hemodialysis patients, 26,166 adult peritoneal dialysis patients, and 1,327 pediatric dialysis patients (652 receiving hemodialysis and 675 on peritoneal dialysis).

### Anemia Management

In 2007, the Food and Drug Administration issued a black box warning for erythropoiesis-stimulating agents after research was published suggesting a link between adverse health outcomes and hemoglobin concentrations  $\geq 13$  g/dL. As a result, the National Kidney Foundation Kidney Disease Outcomes Quality Initiative (KDOQI) revised its anemia management guidelines and recommended a new target hemoglobin concentration for dialysis patients of 11 g/dL–12 g/dL. Together, the black box warning and changes in the KDOQI guidelines resulted in a decrease from 2006 to 2008 in the percentage of dialysis patients with hemoglobin  $\geq 13$  g/dL and an increase in the percentage of patients with a hemoglobin concentration in the targeted range (11 g/dL–12 g/dL). Specifically, the percentage of adult hemodialysis patients with a mean hemoglobin  $\geq 13$  g/dL was 9% in the fourth quarter of 2008, compared with 19% in 2006. For adult peritoneal patients, 14% had a mean hemoglobin  $\geq 13$  g/dL in 2008, compared with 23% in 2006. The percentage of pediatric patients with a mean hemoglobin  $\geq 13$  g/dL was 13% in 2008, compared with 17% in 2006.

Nationally, 41% of all adult hemodialysis patients, 34% of adult peritoneal dialysis patients, and 29% of pediatric dialysis patients had mean hemoglobin concentrations in the 11 g/dL–12 g/dL range in the fourth quarter of 2008. This represents a 9 percentage point increase for adult hemodialysis patients relative to the fourth quarter of 2006, a 4 percentage point increase for adult peritoneal dialysis patients and a 2 percentage point increase for pediatric dialysis patients.

<sup>&</sup>lt;sup>17</sup> Singh AK, Szczech L, Tang KL, Barnhart H, Sapp S, Wolfson M, Reddan D; CHOIR Investigators. Correction of anemia with epoetin alfa in chronic kidney disease. *N Engl J Med.* 2006;355(20):2085-98.

<sup>&</sup>lt;sup>18</sup> National Kidney Foundation Kidney Disease Outcomes Quality Initiative. KDOQI Clinical Practice Guideline and Clinical Practice Recommendations for Anemia in Chronic Kidney Disease: 2007 Update of Hemoglobin Target. CPG AND CPR 2.1 Hemoglobin Target. Available at: http://www.kidney.org/professionals/KDOQI/guidelines\_anemiaUP/guide1.htm

### Dialysis Adequacy

Nationally, the vast majority of hemodialysis patients are being adequately dialyzed, as evidenced by the percentages of patients with mean URR  $\geq$  65% and mean single-pool Kt/V (spKt/V)  $\geq$  1.2. During the fourth quarter of 2008, 89% of adult hemodialysis patients had a mean URR  $\geq$  65, with a range across Networks of 86% to 93%. In 2002–2008, the national percentage of adult hemodialysis patients with mean URR  $\geq$  65 remained stable at 88%–89%. In 2008, 94% (range across Networks = 93% to 96%) of adult hemodialysis patients had a mean spKt/V  $\geq$  1.2. The percentage of adult hemodialysis patients with spKt/V  $\geq$  1.2 remained stable from 2002 to 2008, although it is important to note that Kt/V data are not available for 2004.

Peritoneal dialysis adequacy is commonly measured by mean weekly  $Kt/V_{urea}$  or weekly total creatinine clearance. The percentage of adult peritoneal dialysis patients with a mean weekly  $Kt/V_{urea} \ge 1.7$  ranged from 86% to 91% (national mean = 88%), and the percentage of those with a mean weekly total creatinine clearance  $\ge 60$  L/1.73 m² ranged from 50% to 60% (national mean = 54%). The percentage of adult peritoneal dialysis patients with mean weekly  $Kt/V_{urea} \ge 1.7$  was fairly consistent (range = 88% to 90%) in 2004–2008; however, the percentage of adult peritoneal dialysis patients with mean weekly total creatinine clearance  $\ge 60$  L/1.73 m² decreased by 10 percentage points in this time period.

KDOQI guidelines set the following targets for pediatric dialysis patients: mean delivered  $Kt/V \ge 1.2$  for pediatric hemodialysis patients<sup>19</sup> and mean weekly  $Kt/V_{urea} \ge 1.8$  for pediatric peritoneal dialysis patients.<sup>20</sup> In 2008, 91.4% of pediatric hemodialysis and 80.1% of pediatric peritoneal dialysis patients reached the relevant target. Elab Project data show that for pediatric patients, hemodialysis adequacy remained fairly stable from 2002 to 2008 (although no data are available for 2004), while peritoneal dialysis adequacy ranged from 77% to 84% of patients in 2005–2008.

#### Bone and Mineral Metabolism

The management of bone and mineral metabolism continues to be an important area for quality improvement and intervention. In the fourth quarter of 2008, slightly more than half (53% nationwide; range across Networks = 49% to 56%) of adult hemodialysis patients had a mean phosphorus concentration in the target range of 3.5mg/dL–5.5 mg/dL; 83% (range = 79% to 85%) had a mean calcium concentration in the target range of 8.4 mg/dL–10.2 mg/dL; and 63% (range = 61% to 65%) had a mean calcium concentration in the ideal range of 8.4 mg/dL–9.5 mg/dL. One noteworthy clinical indicator that a hemodialysis patient's mineral metabolism is being managed well is to have both phosphorous and calcium concentrations in the optimal ranges. In 2008, only 45% (range = 42% to 48%) of adult hemodialysis patients achieved this benchmark.

<sup>&</sup>lt;sup>19</sup> National Kidney Foundation Kidney Disease Outcomes Quality Initiative. KDOQI Clinical Practice Guidelines and Clinical Practice Recommendations. 2006 Updates: Hemodialysis Adequacy, Peritoneal Dialysis Adequacy, Vascular Access. I. Clinical Practice Guidelines for Hemodialysis Adequacy. Guideline 8. Pediatric Hemodialysis Prescription and Adequacy. Available at: <a href="http://www.kidney.org/professionals/KDOQI/guideline\_upHD\_PD\_VA/hd\_guide8.htm">http://www.kidney.org/professionals/KDOQI/guideline\_upHD\_PD\_VA/hd\_guide8.htm</a>
<sup>20</sup> National Kidney Foundation Kidney Disease Outcomes Quality Initiative. KDOQI Clinical Practice Guidelines and Clinical Practice Recommendations. 2006 Updates: Hemodialysis Adequacy, Peritoneal Dialysis Adequacy, Vascular Access. II. Clinical Practice Recommendations for Peritoneal Dialysis Adequacy. Clinical Practice Recommendations for Guideline 6: Pediatric Peritoneal Dialysis. Available at: <a href="http://www.kidney.org/professionals/KDOQI/guideline\_upHD\_PD\_VA/pd\_rec6.htm">http://www.kidney.org/professionals/KDOQI/guideline\_upHD\_PD\_VA/pd\_rec6.htm</a>

With regard to adult peritoneal dialysis patients, 55% (range across Networks = 49% to 58%) had a mean phosphorus concentration in the target range of 3.5 mg/dL–5.5 mg/dL; 79% (range = 74% to 82%) had a mean calcium concentration in the target range of 8.4 mg/dL–10.2 mg/dL; and 58% (range = 54% to 60%) had a mean calcium concentration in the ideal range, 8.4 mg/dL–9.5 mg/dL. In 2008, only 45% (range = 39% to 48%) of adult peritoneal dialysis patients were able to meet target values for both phosphorous and calcium concentrations.

Among pediatric dialysis patients, 46% had a mean phosphorus concentration in the target range of 3.5 mg/dL–5.5 mg/dL; 72.5% had a mean calcium concentration in the target range of 8.4 mg/dL–10.2 mg/dL; and 44% had a mean calcium concentration in the ideal range, 8.4 mg/dL–9.5 mg/dL. In 2008, only 34% of pediatric peritoneal dialysis patients were able to meet target values for both phosphorous and calcium concentrations.

These Elab Project findings underscore the need for continued work to improve dialysis patients' outcomes with regard to bone and mineral metabolism.

# Outreach, Education, and Technical Assistance

The ESRD Networks provide a vital service to the renal community by offering information and education to patients, facility/provider staff, nephrologists, primary care providers, other clinicians, and other members of the renal community. Every Network has staff who are content experts on aspects of ESRD care; these professionals share their knowledge and expertise through written materials, training opportunities, and on-site technical assistance.

See Figure 21 for examples of outreach and education activities conducted by the Networks in 2008.

### Outreach to Patients, Practitioners, and Facilities/Providers

Through their websites and newsletters, the Networks provide a range of useful information to patients, practitioners, dialysis facilities, and transplant providers. Every new ESRD patient receives an orientation packet that contains information and resources to help them understand their condition and navigate their treatment.

The Networks also take a proactive approach in reaching out to patients and practitioners by:

- Providing information and resources such as flyers and posters to dialysis facilities to be posted in patient waiting areas
- Mailing or faxing information on relevant clinical issues and new developments in ESRD care
- Helping dialysis facilities and transplant providers stay informed about product and medication recalls, including voluntary recalls and recalls imposed by the Food and Drug Administration
- Sharing resources from other sources, e.g., the National Patient Safety Foundation in conjunction with National Patient Safety Awareness Week, the National Kidney Foundation (NKF), and the American Association of Kidney Patients (AAKF)
- Holding patient and family conferences with speakers on topics of interest as well as opportunities for information sharing and mutual support.

The patient representatives who belong to each Network's Patient Advisory Committee play a role in Network outreach, as do the patient and facility representatives on the Network Council. Members of these advisory bodies are able to provide information and resources to their respective facilities, identify information needs, and encourage participation in Network events such as patient/family conferences.

#### Websites

Each of the 18 ESRD Networks has a website that provides information of interest and importance to the renal community. Some Network websites offer information in languages other than English.

All Network websites offer content that includes the Network's contact information, details on the Network's complaints and grievance policy, information on emergency planning and preparedness, Network-area data, and Network reports, including Annual Reports. Network websites offer (or link to) a wide range of additional materials and tools developed by the Network itself, other ESRD Networks, CMS, and other organizations.

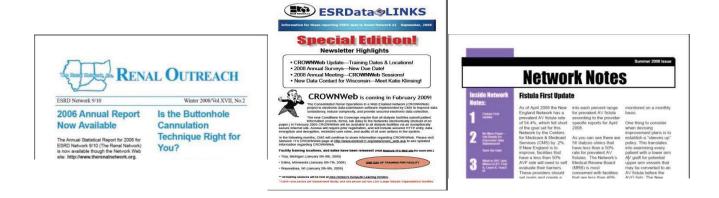
Network websites are monitored by CMS, and content is reviewed regularly, ensuring that the information offered is up-to-date and that sites are in compliance with CMS accessibility and security requirements.



#### Newsletters

All 18 ESRD Networks produce one or more newsletters as part of their CMS contract deliverables. The focus of these newsletters varies by Network. Many Networks have both a patient newsletter and one or more newsletters for renal professionals. Some Networks have Spanish-language patient newsletters.

The Networks' patient-focused newsletters present information designed to improve patients' understanding of their disease and enhance their quality of life, including informative articles, dialysis-friendly recipes, ESRD-related puzzles, and a list of useful websites. Information about the Network's Patient Advisory Committee and complaint and grievance procedures may also be included.



### **Annual Reports**

Each Network prepares an Annual Report (available in hard copy and/or on the Network's website), which describes the ESRD Network Program; Network activities performed to meet CMS goals; the Network's plan for monitoring facility/provider compliance with CMS goals; data on Network-specific and national patterns or profiles of care; results of Network quality improvement projects; and other information as directed by CMS.

#### **New ESRD Patient Orientation Packets**

Since 2000, each new ESRD patients has received a New ESRD Patient Orientation Packet (NEPOP). In 2008, the NCC distributed more than 108,000 NEPOPs (see Figure 22).

Once an ESRD Medical Evidence Report Form (Form CMS-2728) is entered into the Network data system for a new patient, a NEPOP is mailed to the patient's residence. In 2008, the NEPOP included the following:

- A Medicare beneficiary letter from the CMS Administrator
- A letter from the Network Executive Director
- Medicare Coverage of Kidney Dialysis and Kidney Transplant Services (CMS booklet)
- You Can Live (CMS booklet)
- Knowledge, Choice, Control! (NKF brochure)
- *AAKP Resources* (AAKP brochure)
- Vascular Access is an HD Patient's Lifeline (CMS brochure)
- Dialysis Facility Compare (CMS brochure)
- *Preparing for Emergencies*: A Guide for People on Dialysis (CMS booklet).

The NCC receives undeliverable NEPOP envelopes from the U.S. Postal Service monthly. The NCC provides a list of returned envelopes to each Network on a monthly basis, and the Networks are required to research every return to try to make sure that each NEPOP reaches the intended recipient.

In September 2008, the NCC introduced a computerized system designed to streamline the NEPOP tracking and reporting process and reduce data collection and entry errors. The new system, labeled the New ESRD Mailing Organizer (NEMO), runs on a Microsoft Access platform.

#### Support for Employment and Vocational Rehabilitation

As outlined in each Network contract, the Networks are required to annually supply information making patients and providers aware of vocational rehabilitation programs that are available in their

area. Facilities are surveyed by the Networks to determine the demographics of patients aged 18–54 years who are employed through a vocational rehabilitation program or are in school (see Table 20).

Activities conducted by the Networks to encourage employment and vocational rehabilitation include development and/or distribution of brochures and other written materials, e.g., the Life Options publication, *Employment: A Kidney Patient's Guide to Working & Paying for Treatment*; posting contact information for vocational rehabilitation programs on the Network's website; mailing this information to dialysis facilities; advocating for patients who are threatened with job loss; referring patients and potential employers to advocacy and disability rights organizations; and honoring employers who hire ESRD patients.

#### **Patient Education**

The Networks distribute brochures, booklets, and other educational materials to patients, including materials developed by the Network itself, by other Networks, and by national and local renal organizations. These materials address topics such as treatment options, community resources, patients' rights, complaint and grievance procedures, emergency and disaster preparedness, and Medicare coverage policies.

The Networks also provide education to ESRD patients through workshops and conferences. Some Networks hold annual patient and family conferences, sometimes in conjunction with partners such as the NKF and the AAKF; some Networks hold these events more frequently than once a year.

#### **Professional Education**

Providing education for dialysis facility staff and other renal professionals is a major focus of the Networks. Typical activities include:

- Regularly scheduled conference calls with dialysis facility staff
- WebEx presentations on relevant topics
- Online courses that can be used by facilities for training new staff and for inservice training
- Onsite training sessions for facility staff
- Discipline-specific education programs for professionals such as nurses, dietitians, nephrologists, primary care practitioners, and surgeons.

#### Education on New ESRD Conditions for Coverage

CMS issued new ESRD Conditions for Coverage (CfCs) on April 15, 2008, and Interpretive Guidance for the new CfCs in October 14, 2008. The Networks made a major effort to educate dialysis facilities on the new CfCs. For example:

• Network 8 developed a desktop resource that included highlights from the interpretive guidance document, questions submitted to CMS about the Conditions, the Measures Assessment Tool (MAT), and information related to the waiver process.

- Networks 9 and 10, in collaboration with the Renal Physicians Association and two LDOs (DaVita and Fresenius Medical Care) co-sponsored a symposium on the responsibilities of medical directors under the new CfCs.
- In response to the new CfCs, **Networks 9** and **10** developed Quality Assessment and Performance Improvement (QAPI) Templates for vascular access management, dialysis adequacy, anemia management, infection control, patient satisfaction and grievances, and medical injuries and errors. These resources were made available on the Networks 9/10 website.
- In October 2008, **Network 15** staff members conducted a series of three educational WebEx offerings for dialysis facilities to help orient them to the new regulations and Interpretive Guidance. Topics included an overview of the CfCs, infection control and the physical environment, water regulations and reuse, patient assessments, care plans, medical records, and developing a quality assessment and performance improvement program.
- The Patient Services Coordinator of **Network 16** led a Community Task Force on the CfCs. The Task Force created educational materials, webinars, PowerPoint presentations, and other resources. The Task Force received special recognition and an award from CMS for training social workers on the CfCs.

### **Annual Meetings**

The Networks offer educational sessions focusing on aspects of ESRD care at their Annual Meetings. The Networks also use these meetings to encourage quality improvement by recognizing facilities that have demonstrated outstanding performance or major improvement during the year.

#### **Conference Presentations**

The Networks devote considerable resources to educating members of the renal community through presentations at state or local professional conferences and provider meetings. In addition, Network subject matter experts are in demand as presenters at national conferences. For example, Network personnel and Board members co-authored several presentations and posters for the American Society of Nephrology's Renal Week 2008 Annual Meeting & Scientific Exposition, November 4–9, Philadelphia, Pennsylvania. These 2008 Renal Week presentations included the following:

- Bond TC, Krisher J, McClellan W. Association of influenza immunization with mortality in 3 ESRD Networks.
- Bond TC, Patel PR, Krisher J, Deane J, Strott K, McClellan W. Measuring the impact of a quality improvement intervention for influenza vaccination among ESRD clinics: a group-randomized evaluation.
- Kanda E, Bond TC, Krisher J, McClellan W. Adequacy of care before and after starting hemodialysis are associated with individual patient and treatment center mortality.

- Kipp A, Page MJ, Williams T, Wasse H, William McClellan W. Urban-rural disparities in arteriovenous fistula use at hemodialysis initiation.
- Kipp A, Wasse H, McClellan W. Improvements in facility-specific arteriovenous fistula use among prevalent hemodialysis patients between 2004 and 2006 in ESRD Network 5, 6, 8, 11, and 13.
- Kipp A, Williams T, Page M, Kleinbaum D, McClellan W. Community poverty and arteriovenous fistula use at hemodialysis initiation.
- McClellan AC, Waller L, McClellan WM. Low rates of pre-ESRD nephrology care (pre-care) and of incident arteriovenous fistulae (AVF) cluster geographically and among ESRD treatment centers.
- McClellan WM, Wasse H, McClellan AC, Holt J, Krisher J, Waller LA. Geographic intensity of poverty and arteriovenous fistula outcomes in ESRD patients.
- Parikh DS, Kipp AP, Inrig JK, Krisher J, Szczech LA, McClellan W, Patel UD. Veterans more likely to start hemodialysis with an arteriovenous fistula.
- Song EY, McClellan WM, McClellan A, Gadi R, Krisher J, Clay M, Freedman BI. The effect of neighborhood characteristics on family history (FH) of ESRD.
- Spergel LM, Lynch JR, Rowland J, McClellan WM. Has Fistula First caused an increase in catheter prevalence?
- Spergel LM, Lynch JR, Rowland J, McClellan WM. Is the CMS Fistula First target of 66% for prevalent arteriovenous fistula (AVF) feasible?

Network authors included Janet R. Lynch, PhD, CPHQ, **Network 5** Deputy Director; Jenna Krisher, **Network 6** Executive Director; Margo Clay, **Network 6** Director of Information Management; William McClellan, MD, MPH, **Network 6** Medical Review Board member; Jan Deane, **Network 11** Quality Improvement Director; Karen L. Strott, RN, CPHQ, **Network 15** Director of Quality Improvement. Lawrence M. Spergel, MD, was Clinical Chair of the Fistula First Breakthrough Initiative.

#### Contributions to the Professional Literature

Staff members from several Networks published articles in peer-reviewed journals, articles in trade publications, and book chapters in 2008, as shown in Figure 23.

In addition, the *Journal of the American Society of Nephrology* published the results of a study that used data from one of the Networks (**Network 6**). See: Volkova N, McClellan W, Klein M, Flanders D, Kleinbaum D, Soucie JM, Presley R. Neighborhood poverty and racial differences in ESRD incidence. *J Am Soc Nephrol.* 2008 Feb;19(2):356-64. Epub 2007 Dec 5.

Two articles featuring Network activities appeared in national trade publications in 2008. The October 2008 issue of *Nephrology News & Issues* featured an article titled "Renal Physicians Association launches 'Keep Kidney Patients Safe' website," which mentions the 5 Diamond Patient Safety Program developed by **Networks 1** and **5**. An article on the Texas ESRD Emergency Coalition, titled "Hurricane Ike Tests ESRD Emergency Plans," was featured in *NurseWeek* magazine on December 8, 2008.

#### **Technical Assistance**

The Networks serve as a resource to dialysis facilities, providing technical assistance as needed or on request. In addition to responding to telephone and e-mail inquiries, Network staff members make onsite visits to support facilities in providing the most appropriate care to dialysis patients. Specific clinical issues and questions about how to complete CMS forms are among the topics addressed.

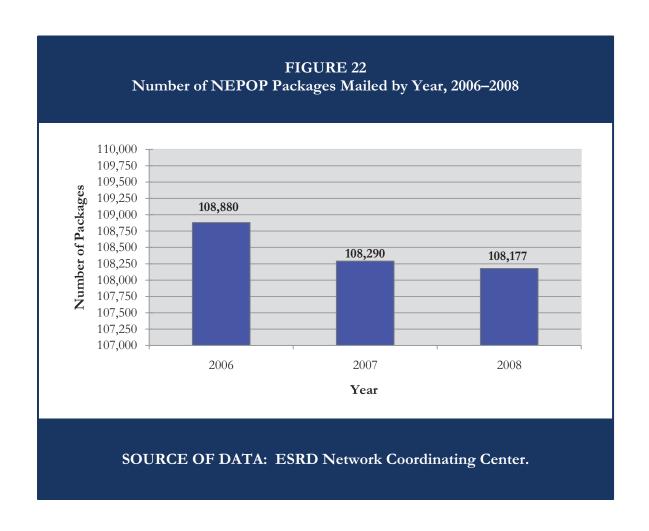
| FIGURE 21 Examples of Network Outreach and Education Activities, 2008 |   |  |
|---|---|--|
| NETWORK 1   | Patient Education Cards: In April 2008, Network 1 sent dialysis unit nurse managers and social workers a set of five laminated patient education cards held together by a metal ring. These "Dialysis Unit Wisdom" cards offered snapshot reminders for patients on influenza vaccinations, hand hygiene, mutual respect, vascular access, diet tips, safety tips, and other helpful hints. Also included was a disaster "to do" list. The Network suggested that each facility hang the set of cards in the patient waiting area.  |  |
| NETWORK 1   | Patient Education Booklet: Network 1's Patient Advisory Committee updated the patient orientation education booklet "Your New Life" to better reflect current renal health care practices. The 31 pages contain information on hemodialysis, peritoneal dialysis, kidney transplantation, and other treatment choices. The booklet also includes tips on nutrition, coping, and travel as well as contact information for kidney-related resources. This popular booklet is frequently requested by dialysis facilities and physicians.   |  |
| NETWORK 1   | Educational Program for Patient Care Technicians: In April 2008, Network 1 held two all-day educational programs for patient care technicians, "Time Out For Techs," approved for contact hours through the National Association of Nephrology Technicians/Technologists. The topics included patient safety, infection control, renal transplantation, teamwork, professionalism, and cannulation skills. A total of 225 patient care technicians attended.  |  |
| NETWORKS 1<br>AND 5   | <b>5 Diamond Patient Safety Program:</b> In 2008, Networks 1 and 5 launched the 5 Diamond Patient Safety Program. This program offers a series of modules for staff inservice training. The program is designed so that each dialysis facility that completes one module, and submits documentation on implementation of the module and the outcome achieved, is recognized with one "Diamond"—up to a maximum of five Diamonds during the participation period. Dialysis facilities that complete five modules are given public recognition and awarded a plaque. At the end of 2008, Network 1 had registered 26 facilities for this new safety project. Seven of these providers successfully completed five modules and were awarded 5 Diamond plaques. Network 5 registered 128 facilities (41% of the facilities in the Network area) in 2008; 12 facilities achieved 5 Diamond status, and another 27 earned from 1 to 4 Diamonds. |  |

| NETWORK 4 | Physician Symposium and Toolkit: Network 4's renal coalition, the PennDel CKD Partnership, collaborated with the National Kidney Foundation of the Alleghenies, the University of Pittsburgh, and the University of Pittsburgh Medical Center to host a dinner symposium for medical professionals on September 20, 2008, in Hershey, Pennsylvania. This educational program, titled "A Multi-Disciplinary Approach: CKD Management for Primary Care Providers," was designed for primary care physicians, cardiologists, nephrologists, endocrinologists, certified renal nurse practitioners, physician assistants, and other medical professionals. A toolkit prepared for the symposium included a slide presentation, a CKD Stage 1–5 Algorithm of Care, a Pocket Guide, and a list of educational resources.  |
|-----------|---|
| NETWORK 4 | AVF Workshop for Surgeons: Network 4 collaborated with the University of Pittsburgh School of Medicine's Center for Continuing Education in the Health Services to offer a workshop for surgeons titled "The Access of Choice for ESRD Hemodialysis Patients: An Arteriovenous Fistula." This full-day seminar, held on April 25, 2008, in Hershey, Pennsylvania, was designed for general vascular and transplant surgeons active in vascular access procedures. Presentations included: "Cimino and Brachial AV Fistulae"; "Proximal Radial AVF"; "Vein Preservation"; "Indications for Bridge Fistulae"; "Transposition AV Fistulae"; "Difficult Access Patients"; "Steal Syndrome Management"; and "Tunneled Dialysis Catheters." A demonstration on venous mapping was also offered. The program was attended by more than 75 surgeons, residents, and nurses. Continuing medical education credits were offered through the School of Medicine.   |
| NETWORK 4 | "Just-in-Time" Training Collaborative: Network 4 collaborated with the Department of Emergency Medicine at the University of Pittsburgh School of Medicine to develop a "Just-In-Time" teaching module. The objective of this project was to develop and evaluate a training program that would provide just-in-time cross-training of non-dialysis staff to augment dialysis staff during a prolonged public health emergency or disaster. Five modules were developed with input from an educator and several nurse managers from local units: "Basics"; "Principles of the Kidney & Dialysis"; "Hemodialysis Devices"; "Hemodialysis Procedure"; and "Troubleshooting." Two pilot training sessions were held in December 2008, one with medical students and the other with secretaries, billers, social workers, and dietitians.   |
| NETWORK 5 | Academic Detailing Manual: Network 5 developed an Academic Detailing Manual as part of an intervention to increase AVF placement rates in facilities with low rates. Low-performing facilities were divided into two subgroups: a low-intensity intervention group and a high-intensity intervention group. Facilities in both subgroups were provided with monthly data feedback on the facility's AVF rate, including comparisons to average performance within the Network area and the U.S. as a whole, as well as to a benchmark rate for the Network area. Facilities in both subgroups also received the Fistula First Change Concept Package. The high-intensity intervention facilities also received physician-to-physician educational outreach in the form of three academic detailing contacts provided over the phone by members of the Network's Medical Review Board. The Academic Detailing Manual developed for this project included specific scripts for the technical detailer to follow along with related resource materials. Facilities enrolled in the high-intensity subgroup discussed process improvements during the detailing calls. Facilities in the low-intensity subgroup were asked to document process changes made throughout the year; this information will be collected at the end of the project. Both groups received educational materials on request. This project continues into the spring of 2009. |
| NETWORK 6 | <b>Provider Education Calendar:</b> Network 6 developed a calendar for dialysis facilities that focused on a quality of care topic each month. After the calendars were mailed to facilities in mid-2008, a monthly packet was sent out with information related to the   |

| calendar topic. For example, in December the calendar focused on CROWNWeb, and facilities received a notebook of materials to help them prepare for and enroll in CROWNWeb. Other calendar topics included vascular access, treatment options, and disaster planning. An evaluation of the project showed that facilities found the materials useful and timely.  Complaint and Grievance Training Modules: Based on a trend analysis of data from the Network's complaint and grievance subcoding project, Network 6 developed three on-line training modules for dialysis facility staff:  • Boundaries and Professionalism  • Understanding the Mental Health of Our Patients  • Building Relationships that Work  Fistula First/Catheter Out WebEx Series: A quarterly WebEx conference series started by Networks 9 and 10 in 2007 continued into 2008. Representatives from facilities with high AVF rates presented at these sessions. Presenters explained their best practice models for specific topics and provided related tools and resources to participants. Topics included "Early Referral to the Vascular Surgeon" and "Changing Patient Culture," among others. The WebEx conferences and accompanying materials were made available on the Networks' website.  Information on Self Care: A packet on "Patient Self-Care in the Dialysis Unit," including information for patients and staff, was sent to dialysis facility head nurses. For patients, the material included an article titled "Self-Care Increases Personal Control" by Mary Ann Webb, MSN, RN, CNN, the Networks' Quality Improvement Coordinator. The material for staff included an article titled "Self-Care Increases Personal Control" by Mary Ann Webb, MSN, and the Network of the Network are for patients. The 12-minute video features dialysis and transplant patients talking about how a regular exercise program improved their health and sense of well-being. In addition to the interviews with patients, the video includes vignettes showing them exercising.  Patient and Staff Brochures: Network 12 developed a num |
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| rehabilitation offices; and a brochure that defined kidney transplantation and summarized  |
| donor types.  Patients' Rights Poster: Network 12 developed a poster, in collaboration with its  |
| Patient Advisory Committee, to educate ESRD patients about their rights and  |
| NETWORK 12 responsibilities in light of the new Conditions for Coverage. The poster was mailed to all  |
| dialysis units with a cover letter requesting that it be posted in a prominent location for  |
| patient access. The resource was also distributed to the State Survey Agencies in the  |
| Network area.  |
| Transplant Booklet: Network 12 performed a gap analysis in 2008 to identify topics   |
| for educational materials to meet the needs of the renal community. Based on a noted   |
| NETWORK 12 increase in kidney transplant demands in the Network area, Network staff reviewed and   |
| revised a transplant booklet. The resource was distributed to all dialysis facility social   |
| workers in the Network area and made available on the Network website.   |
| Professional Education on Transplant Issues: Network 12 hosted an education  |
| <b>NETWORK 12</b> session attended by more than 400 dialysis center personnel on January 10, 2008, in  |
| Kansas City, Missouri. The session introduced a patient education program titled Explore   |

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|                    | Transplant developed by Washington University researcher Amy Waterman, addressed concerns that dialysis patients commonly have about transplantation, and identified          |
|                    | patient and system barriers that prevent patients from pursuing transplantation. A  |
|                    | collaboration between Dr. Waterman and Network 12 will allow for a Network-wide   |
|                    | rollout of the Explore Transplant program in 2009.  |
|                    | "Guide to Care Agreements": Network 12 created a "Guide to Care Agreements"   |
|                    | booklet to help dialysis facilities determine when a care agreement may be helpful and to   |
| NETWORK 12         | provide information on how to structure effective care agreements. Emphasis is placed   |
|                    | on avoiding the use of "behavior contract" terms with patients. The booklet   |
|                    | recommends that facility staff use the term "behavioral agreement" when addressing  |
|                    | difficult patient situations.   |
|                    | Pediatric Resource Toolkit: The Network created a Pediatric Advisory Council as a   |
| NETWORK 12         | subgroup of its Medical Review Board. Based on input from the committee, the Network  |
| NET WORK 12        | developed a comprehensive pediatric resource toolkit and distributed it to all pediatric  |
|                    | dialysis units in the Network area for professionals' use in addressing the unique needs of   |
|                    | this population.  |
|                    | Training for Network Representatives: Network 13 developed the Network Patient  |
|                    | Representative Training Packet, which includes materials designed to orient ESRD  |
| NIETWODK 42        | patients and their facility representatives to the Network-developed patient-to-patient   |
| NETWORK 13         | outreach program. The materials explain the role of a Network Patient Representative in   |
|                    | the dialysis facility. The Network also developed a business card for facility representatives, which allows these patient leaders to reach out to the rest of their dialysis |
|                    | facility's patient population.  |
|                    | Regularly Scheduled WebEx Presentations: In 2008, the Network provided regularly  |
|                    | scheduled, discipline-specific WebEx educational opportunities. These sessions, led by  |
|                    | Network staff or other renal professionals, were scheduled at multiple times to maximize  |
| NETWORK 13         | staff participation. WebEx presentations on clinical and patient services issues provided   |
|                    | additional educational opportunities for dialysis facility staff. Facilities were notified  |
|                    | monthly of WebEx offerings through blast fax and listing on the Network 13 website.   |
|                    | An average of 37 facility staff participated per session.   |
|                    | <b>Tip Sheets:</b> In 2008, the Network's Patient Services Department developed a series of   |
| > 177777110 DVI 45 | "Tip Sheets" to address issues for which the Network frequently receives requests for   |
| NETWORK 15         | resources. These Tip Sheets, which were sent to all facilities in the Network area, focused   |
|                    | on the importance of a complete patient assessment, health literacy, cultural competency  |
|                    | and limited English proficiency, and strategies for addressing abusive behavior.  Vascular Access PowerPoint Presentations: The QI Director developed and                     |
|                    | presented several new PowerPoint technical education presentations:   |
|                    | Reducing Long-Term Catheters  |
|                    | Access and Their Issues   |
|                    |   |
|                    | • The Good, the Bad, and the Ugly—What Happened to My Buttonhole Sites?   |
| NETWORK 16         | Controlling Buttonhole Infections and Buttonhole Complications  |
|                    | Cannulation: Problems & Troubleshooting   |
|                    | Managing Catheter Dysfunctions for Better Patient Outcomes  |
|                    | Tips for Successful Buttonhole Cannulation  |
|                    | Vascular Access Assessment and Cannulation  |
|                    | Advanced Principles of AVF Buttonhole Management  |
|                    | Tips & Techniques: Save That Vein   |
|                    | The Buttonhole Technique: Conquering the Complications.   |
| NETWORK 16         | Buttonhole Technique Patient ID Card: Network 16's QI Director developed an ID  |
|                    | card for patients using the buttonhole technique to aid medical professionals in  |

|            | preserving AVF buttonhole sites when they are unfamiliar with the patient and/or the         |
|------------|--|
|            | technique. The card reads, "I AM A DIALYSIS PATIENT WITH AN AV FISTULA. I                    |
|            | USE THE BUTTONHOLE TECHNIQUE FOR INSERTING MY NEEDLES."                                      |
|            | Spaces are provided for the patient's name, the name of the dialysis facility, and the       |
|            | facility's phone number. These cards were distributed to all Network area facilities and     |
|            | were made available on the Network's website, resulting in several contacts from             |
|            | individuals outside the Network's service area.  |
|            | "Facility Alert" Binder: Network 17 distributed a brightly colored "Facility Alert"          |
|            | binder to all dialysis facilities in the Network area. Facilities were encouraged to use the |
| NETWORK 17 | binder to compile information received from the Network and communicate it to staff          |
|            | and patients. The information included recalls and product updates from the Centers for      |
|            | Disease Control and Prevention, MedWatch (the FDA's Safety Information and Adverse           |
|            | Event Reporting Program), and other sources.   |



# FIGURE 23

# Journal Articles and Book Chapters Published by Network Authors, 2008

# ARTICLES IN NATIONAL/INTERNATIONAL PEER-REVIEWED JOURNALS

| ARTICLES IN NATIONAL/INTERNATIONAL PEER-REVIEWED JOURNALS |  |
|---|--|
| NETWORKS 1,<br>5, AND 12                                  | Staff members from three ESRD Networks contributed to an article published in the September–October 2008 issue of the <i>Nephrology Nursing Journal</i> , the official journal of the American Nephrology Nurses' Association. The authors of the article included Jaya Bhargava, PhD, Network 1's Information Systems Manager; Roberta Bachelder, MA, Network 1's Patient Services Manager; Renee Bova-Collis, MSW, Network 5's Patient Services Coordinator; and Kimberly F. Thompson, RN, CNN, Network 12's former Patient Services Coordinator. <i>Citation:</i> Thompson KF, Bhargava J, Bachelder R, Bova-Collis R, Moss AH. Hospice and ESRD: knowledge deficits and underutilization of program benefits. <i>Nephrol Nurs J.</i> 2008 Sep-Oct;35(5):461-6, 502; quiz |
|   | 467-8.   |
|   | Network 7 staff member Matthew J. McDonough published a three-part series on CROWNWeb in the journal Nephrology News & Issues.   |
| NETWORK 7   | Citations:  McDonough MJ. CROWNWeb: the evolution of kidney data management (Part 1). Nephrol News Issues. 2008 Mar;22(3):42, 44, 46.  |
|   | McDonough MJ. CROWNWeb: the evolution of kidney data management (Part 2). Nephrol News Issues. 2008 Jul;22(8):51-4.  |
|   | McDonough MJ. CROWNWeb: the evolution of kidney data management (Part 3). Nephrol News Issues. 2008 Sep;22(10):48-50.  |
|   | Network Executive Director Martha Hanthorn, MSW, Quality Improvement Director Lynda K. Ball, MSN, RN, CNN, contributed to an article published in <i>The Journal of V ascular Access</i> .   |
| NETWORK 16  | Citation:  Nguyen VD, Griffith CN, Reus J, Barclay C, Alford S, Treat L, Hanthorn M, Ball L, Lawson L, Ledeen M, Buss J. Successful AV fistula creation does not lead to higher catheter use: the experience by the Northwest Renal Network 16 Vascular Access Quality Improvement Program: four years follow-up. J Vasc Access. 2008 Oct-Dec;9(4):260-8.  Lynda Ball co-authored an article published in the peer-reviewed journal of the European Dialysis and Transplant Nurses Association/European Renal Care Association.  Citation:  Muroma-Karttunen R, Boogaerts M, Spindler B, Wright J, Ball LK, Cruz-Casal M, Pickering L, Goovaerts T, Ross J, Annand J, Van  |
|   | Waeleghem J-P, Shaldon S, Csender J, Brouwer D, Farquhar G,<br>Walker D, Simmonds R, King J, De Vos J-Y, Stragier A, Verhallen<br>AM, van Jaarsveld BC. EDTNA-ERCA Journal Club discussion   |

|   | (Autumn 2007): "Buttonhole cannulation: should this become the default technique for dialysis patients with native fistulas?" <i>J Renal Care.</i> 2008;34(2):101-108.   |  |
|---|--|--|
| ARTICLE IN A NATIONAL TRADE PUBLICATION |  |  |
| NETWORK 16                              | Quality Improvement Director Lynda Ball co-authored an article in the journal Nursing Made Incredibly Easy.  Citation:  Castner D, Ball LK. Red flags: a troublemaking clot. Nursing Made Incredibly Easy! 2008 Jan-Feb;6(1):12-13.  |  |
| ARTICLE IN A STATE TRADE PUBLICATION    |  |  |
| NETWORK 1                               | An article by Peggy J. Lynch, RN, CNN, Network 1's Medical Quality Manager, appeared in the Summer 2008 issue of CONNECTIONS, the newsletter of the of the National Kidney Foundation in Connecticut. The article, titled "Chronic Kidney Disease and Nephrology Referral: When is the Right Time?" is available on the Web at http://www.kidney.org/site/102/newsletter.htm.  |  |
| BOOK CHAPTERS                           |  |  |
| NETWORK 7                               | Lisa M. Hall, MSSW, Community Services Coordinator for Network 7, contributed a chapter to the 5th edition of the Core Curriculum for Nephrology Nursing.  Citation:  Hall LM. The individual with kidney disease: psychosocial impact and spirituality. In: American Nephrology Nurses' Association. Core curriculum for nephrology nursing. 5th ed. Counts CS, editor. Pitman (NJ): ANNA; 2008.  |  |
| NETWORK 14                              | Network 14's Executive Director Glenda Harbert, RN, CNN, CPHQ, contributed a chapter on ethical issues to the 5th edition of the Core Curriculum for Nephrology Nursing.  Citation:  Harbert G. Ethical considerations and dilemmas. In: American Nephrology Nurses' Association. Core curriculum for nephrology nursing. 5th ed. Counts CS, editor. Pitman (NJ): ANNA; 2008.  |  |
| NETWORK 16                              | A chapter titled "Care of the Renal Transplant Recipient" by Quality Improvement Director Lynda Ball was published in the 2 <sup>nd</sup> edition of the <i>All-In-One Care Planning Resource</i> .  Citation:  Ball LB. Care of the renal transplant recipient. In: Swearingen PL.  All-in-one care planning resource: medical-surgical, pediatric, maternity, and psychiatric nursing care plans. 2 <sup>nd</sup> ed. St. Louis (MO): Mosby; 2008. |  |

# Special Projects

### Special Project: ESRD Network Coordinating Center

Since 2003, the End Stage Renal Disease (ESRD) Network Coordinating Center (NCC) has served CMS and the 18 ESRD Networks by providing centralized coordination and support for the operation of the ESRD Network Organization Program. The NCC contract is held by **Network 2**.

The NCC's responsibilities include:

- Providing support to the ESRD Networks and CMS through coordinating and hosting conference calls, providing meeting services, and tracking and compiling Network reports including Quarterly and Annual Reports.
- Providing educational resources to the ESRD community via the NCC website.
- Coordinating the CMS/ESRD Networks' Annual Meeting.
- Mailing a packet of information, the New ESRD Patient Orientation Packet (NEPOP), to every new dialysis patient and tracking the delivery of these packets (see the Outreach, Education, and Technical Assistance Section of this report for more details).
- Preparing reports under CMS guidelines, including this Summary Annual Report (SAR). The SAR condenses patient and facility/provider data and the activities of the 18 ESRD Networks into one document that gives an overview of the state of ESRD care in the United States.
- Annually updating and distributing the Directory of ESRD Network Organizations.

### Special Project: Fistula First Breakthrough Initiative

In 2008, **Network 18** provided administrative support for the Fistula First Breakthrough Initiative under a contract with CMS. Network 18 supported the activities of other Networks in the area of vascular access by providing information and resources, maintaining the Fistula First website (www.fistulafirst.org), and preparing an Annual Report summarizing Fistula First activities. See the **Fistula First Breakthrough Initiative** section of this report for an overview of the initiative and highlights of 2008 Fistula First data.

# Special Project: Kidney Community Emergency Response Coalition

Under contract with CMS, **Network 7** provided administrative support to the Kidney Community Emergency Response (KCER) Coalition in 2008. Among other responsibilities, Network 7 supported a national website (www.kcercoalition.com), maintained a toll-free number, and served as a central coordination point in the event of a disaster to ensure that emergency backups were in place for dialysis patients. For more details, see the **Emergency Preparedness and Response** section of this report.

# Special Project: Quality Infrastructure Support (QIS)

In 2008, **Network 7** continued work on the Quality Infrastructure Support (QIS) Special Project, which supported the development of the CROWNWeb data management system.

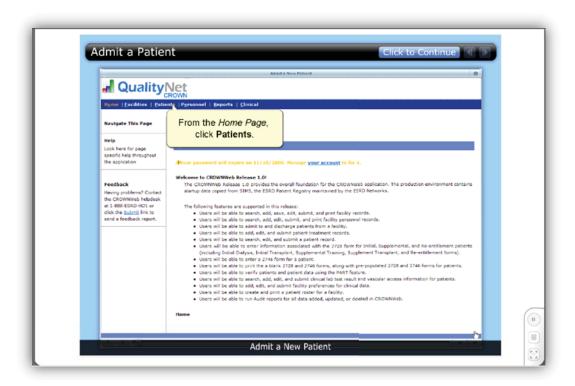
Obtaining input and feedback from the Networks and renal providers has been critical to the successful development of CROWNWeb. The CROWNWeb Responsiveness and Feedback Tree (CRAFT) was developed in 2008 as a method for providing input into the CROWNWeb development process. Monthly conference calls were held to provide information to the renal community and open up lines of discussion regarding progress on the CROWNWeb project.

Network 7 was tasked with developing the business requirements for successful implementation of the CROWNWeb. The Network facilitated a series of Change Control Board meetings for the purpose of refining the business requirements and surveyed business owners and potential customers over the course of the year. Information on the business requirements and the overall direction of CROWNWeb was communicated to the ESRD community and CMS via the CROWN Newsletter, the CRAFT calls, a CRAFT e-mail list, and the www.projectcrownweb.org website.

Development of a single, standardized ESRD data dictionary to support quality improvement was another priority in 2008. The Kidney Data Dictionary (KDD) was delivered to CMS in June. Network 7 was also responsible for designing a process for developing, updating, and retiring KDD elements. A key aspect in developing the KDD was soliciting feedback from the renal community. Network 7 held a series of CRAFT meetings for the purpose of understanding and documenting community needs. Additionally, Network 7 presented a series of teleconferences and WebEx presentations to address questions regarding the KDD elements. The QIS team also fielded comments regarding the KDD that were received via the CRAFT e-mail account.

As part of the QIS contract, Network 7 was responsible for communicating Project CROWNWeb's progress and for building momentum for its release. Marketing activities were conducted via conference presentations and exhibits, publications, and CROWNWeb newsletters. Marketing activities conducted in 2008 put special emphasis on the system's ability to accept and report quality data on a monthly basis. Presentations on CROWNWeb were given at a number of state-level and national meetings. A CROWNWeb exhibit and tutorial were displayed at professional conferences sponsored by organizations including the National Kidney Foundation, the American Nephrology Nurses Association, the National Renal Administrators Association, Renal Physician's Association, and several ESRD Networks. Additionally, Network 7 developed a CROWNWeb mini-booth that was used by five other Networks in 2008. The Network published several articles in renal journals and magazines in 2008, including a series of three articles for Nephrology News & Issues, published in March, July, and September.

As the QIS contractor, the Network was responsible for addressing the CROWNWeb training needs of the renal community. In late 2008, Network 7 developed materials for Instructor-Led Training to be held nationwide in 2009. These materials were pilot tested with two Florida facilities. Auditory (lecture), visual (media and slides), and kinesthetic (hands-on use of the system) learning styles were addressed in the instructor-led training. Network 7 also created a suite of interactive Online Training courses designed to educate users on CROWNWeb. Visual and kinesthetic learning styles were addressed in online training through the use of slides, movies, and an interactive "walk through" of CROWNWeb application screens. The online tutorials were posted to www.projectcrownweb.org.



## Special Project: Network Information Technology Support (NWITS)

In 2008, **Network 2** served as the contractor for the Network Information Technology Support (NWITS) Special Project. The Network's principal role was the creation of the CROWN Help Desk to support the ESRD end-user community. The CROWN Help Desk was accessible by phone, by email, or online.

The Help Desk managed user accounts, provided support for the batch data reporting process, and responded to service requests from users. The Help Desk was responsible for processing the QualityNet Identity Provisioning System (QIPS) Account Form, the vehicle for applying for access to the system. The CROWN Help Desk also processed Batch Delegation of Authority Forms (CMS-10268). Dialysis facilities were required to submit CMS-10268 forms in order to participate in the electronic data submission feature of CROWNWeb.

As of December 31, 2008, the CROWN Help Desk had processed approximately 4,000 CMS-10268 forms. Network 2 was able to provide support to CMS in fine-tuning the batch forms management process.

# Partnerships and Collaborations

As in past years, the Networks took an active role in the creation and ongoing implementation of a variety of collaborative partnerships in 2008. The Networks' collaborative efforts involved communication and coordination with renal partners at the local, Network area, and national levels. Through these collaborations, the Networks remained in the forefront of emerging issues, creative problem solving, and innovation in care for ESRD patients.

The Networks partnered with a wide range of organizations in 2008, such as the National Kidney Foundation (NKF), the American Kidney Fund (AKF), the American Association of Kidney Patients, the National Association of Nephrology Technicians/Technologists, the National Renal Administrators Association (NRAA), the Council of Nephrology Social Workers (CNSW), the American Nephrology Nurses' Association (ANNA), the Renal Physicians Association (RPA), the American Society of Nephrology, the National Hospice and Palliative Care Organization (NHPCO), the Association of Health Facility Survey Agencies, the Life Options Rehabilitation Advisory Council, the Medical Education Institute, the United Network for Organ Sharing, the United States Renal Data System Coordinating Center, the National Institute of Diabetes and Digestive and Kidney Diseases of the National Institutes of Health, independent dialysis corporations, and large corporate dialysis organizations (LDOs).

## Partnerships with State Survey Agencies

An important component of each Network's collaborative work is a relationship with the State Survey Agency(ies) in the Network area. Ongoing communication between the Networks and State Agencies helps ensure facilities' compliance with the Networks' quality of care and data goals, as well as compliance with the ESRD Conditions for Coverage. Ongoing communication and coordination with state surveyors ensures that consistent messages are provided to facilities and that performance issues are readily identified.

A collaboration between **Network 2** and the New York Department of Health led to the development of a Quality Assessment Performance Improvement (QAPI) project in 2008. Network staff worked with facilities identified by state surveyors, offering support and technical assistance. Also through this collaboration, a tool was developed to standardize the information provided to surveyors by the Network. This information included the facility's fistula rate and fistula goal, the Network-wide fistula rate, the facility's forms compliance rate, and the number of complaints, involuntary discharges, and involuntary transfers in the last 12 months, and any quality of care concerns.

In 2008, **Network 3** worked closely with the health departments in New Jersey and Puerto Rico. Quarterly conference calls with each of the departments covered issues such as involuntary discharges, emergency preparedness activities, quality of care issues found during visits, and newly opened or closed facilities. Prior to visiting facilities, health department surveyors contacted Network 3 to obtain data, including the facility's fistula and catheter rates, fistula and catheter goals as set by the Network, the facility's forms compliance rate, and the number of complaints and involuntary discharges in the last 12 months.

In 2008, ESRD surveyors from the Texas Department of State Health Services (DSHS) requested assistance from **Network 14**'s QI staff and Medical Review Board (MRB) in drafting revisions to the Texas ESRD facility licensure rules. Over the course of the year, Network staff worked closely with the DSHS ESRD surveyors, providing technical assistance and information, including facility-specific and national clinical performance data.

DSHS referred 10 facilities to Network 14's MRB in 2008 for potential or serious concerns regarding the quality, safety, and appropriateness of care in these facilities. The MRB assisted DSHS by reviewing the concerns and recommending directed Corrective Action Plans, including use of monitors and managers as indicated. Network staff and the MRB also participated in monitoring and improvement activities for 15 facilities referred to the MRB during previous years. When DSHS required the use of temporary managers or monitors, periodic updates on their assessment of corrective actions were submitted to the Network and MRB. At a facility's request, or when indicated by deficient processes, the Network assisted with the development of corrective actions and provided education, technical assistance, and support. Of the 25 facilities, two were unable to meet the minimum standards of care and were closed. With assistance from the Network, all patients were transferred to other facilities in the area. One facility withdrew from participation in the ESRD licensure program after it was found to have provided substandard care to its dialysis patients. This facility elected to continue to provide dialysis care under the home health program. The Network contacted the Texas Department of Aging and Disability Services (DADS) regarding the care being provided to dialysis patients by this facility, citing the serious patient health and safety quality of care issues identified under the ESRD licensure program. The facility was then surveyed by DADS personnel, and the complaint was substantiated.

# Collaborations with Quality Improvement Organizations (QIOs)

CMS funds a national network of 53 Quality Improvement Organizations (QIOs) that work to improve the quality and efficiency of health care for Medicare beneficiaries and others. The QIOs are located in the 50 U.S. states, Washington, DC, Puerto Rico, and the Virgin Islands, with three other U.S. territories (American Samoa, Guam, and the Northern Mariana Islands) covered by the QIO contract for Hawaii.

The QIOs' latest three-year contract cycle began on August 1, 2008. As part of their contractual work, a number of the QIOs are focusing on improving care for individuals with chronic kidney disease (CKD). These QIOs work directly with primary care physicians and nephrologists to increase the adoption of evidence-based standards for CKD care. As part of this effort, these QIOs are also responsible for convening or joining a coalition that includes the ESRD Network and other CKD stakeholders in the QIO's state/jurisdiction. The goal of these coalitions is to provide a forum in which stakeholders can work together to increase access to care for individuals at risk for and/or diagnosed with CKD, to improve the quality of CKD care, and to improve medical outcomes for CKD patients. Coalitions are expected to identify priorities and recommend changes at the system level. Collaboration between ESRD Networks and QIOs is essential to the success of the QIOs' CKD activities.

### Kidney Community Emergency Response (KCER) Coalition

See the Emergency Preparedness and Response section for details on this national collaboration.

### Kidney End-of-Life (EOL) Coalition

Coordinated end-of-life care is an essential component of quality ESRD care. The national Kidney End-of-Life (EOL) Coalition focuses on helping ESRD patients express their end-of-life treatment desires; on supporting implementation of end-of-life and palliative care programs in dialysis units; and on meeting the educational needs of patients, families, and health care professionals with respect to end-of-life issues.

The EOL Coalition grew out of a 2004 conference sponsored by **Network 5**. Alvin Moss, MD, FACP, of West Virginia University, chairs the coalition. Members include representatives from CMS, the ESRD Networks, all of the LDOs, NKF, AKF, NRAA, CNSW, ANNA, RPA, NHPCO, hospice agencies, medical education organizations, attorneys, and patient organizations. A Steering Committee provides oversight and leadership for coalition activities, and four work groups report to the Steering Committee: the Hospice Work Group, the Physician Education Work Group, the Pain Management Work Group, and the Website Review Work Group.

The coalition's website, www.kidneyeol.org, offers a range of information related to end-of-life care for CKD patients. By the end of 2008, the number of visits to the website and the number of downloaded documents were each approaching 4,000 per month. The coalition also sponsors a listsery, hosted by the NKF.

In 2008, the Network mailed 3,936 copies of a brochure developed by Network 5, "Advance Care Planning: For Dialysis Patients and Their Families" to dialysis community partners across the country. The brochure was also reproduced by DaVita, an LDO, to distribute to its facilities nationwide.

Coalition members gave presentations at a number of national meetings in 2008. For example, in April, the coalition Chair, Dr. Moss, spoke at the National Kidney Foundation's Clinical Team Conference in Dallas, Texas. In May, two coalition members presented on pain management on a national AAKP teleconference. In August, Dr. Moss and Network 5 Executive Director Nancy Armistead presented at the NHPCO's 2nd Annual Conference on access to palliative care and hospice.

Additional highlights of coalition activities in 2008 include the following:

- A pain management tool was developed for physician use. The tool, which provides details on appropriate medications and dosing regimens, was piloted in selected dialysis facilities.
- An article titled "ESRD Challenges Hospice to Assure Appropriate Access," which contained information and interviews with coalition members, was published in an NHPCO newsletter.
- The CNSW manual *Standards of Practice for Nephrology Social Work* was revised to include a piece about the coalition.

# **Emergency Preparedness and Response**

ESRD patients are uniquely vulnerable in emergency or disaster situations. In the event of severe weather conditions, flooding, and other emergencies or disasters, the Networks work hard to ensure that ESRD patients are located and that they receive life-sustaining services in alternative facilities when they are unable to reach their usual facilities or their usual facilities are closed. Each Network is required to have an Emergency and Disaster Response Plan in place, and coordination and support are provided at the national level by the Kidney Community Emergency Response (KCER) Coalition.

As part of their emergency/disaster planning efforts, the Networks collaborate with local, state, and federal agencies to educate them on the special needs of ESRD patients and help ensure a coordinated response. For example, in 2008, **Network 2** partnered with the New York City Office of Emergency Management to make sure that the needs of ESRD facilities and patients were addressed in statewide emergency and disaster planning. As part of this effort, Network 2 developed a Critical Asset Survey that was sent to all dialysis facilities in the state in September 2008. The survey asked for information on facility resources (e.g., staff and equipment) to help Network staff provide support to facilities in the event of an emergency/disaster.

When Hurricanes Gustav and Ike swept into the Gulf Coast region in late August and early September 2008, **Network 13** collaborated with facility staff, local volunteer agencies, CMS, the Louisiana, Arkansas, and Oklahoma emergency management and State Survey Agency offices, the Louisiana Vulnerable Patient Advocacy Coalition (VPAC), and the KCER Coalition to ensure that dialysis and transplant patients were able to access the care and medications they needed. The Network also worked with large dialysis organizations and their facilities to make sure that all patients were accounted for and treated in locations as convenient to them as possible.

Network 14 has worked closely since 2005 with the community-based Texas ESRD Emergency Coalition (TEEC) to partner with the Department of State Health Services in enacting a comprehensive statewide emergency plan for ESRD patients in Texas. During Hurricanes Gustav and Ike, TEEC activated its mobile command center for the first time since its inception. Network staff and renal community volunteers handled more than 1,700 incoming calls. The Command Center was housed at the Dallas County Health and Human Services Medical Operations Command Center. This location allowed the Network and TEEC to coordinate resources with local officials and maintain an ongoing flow of information.

In addition to working with local, state, and national agencies and organizations, the Networks work very closely with individual dialysis facilities to make sure that patients' needs are met. The state of Louisiana was particularly hard-hit by emergency and disaster situations in 2008; **Network 13** worked with facilities to respond to: disruption of the water supply in Shreveport, Louisiana (January 10, 2008), a tornado in Arkansas (February 6–7, 2008), flooding and severe weather in Shreveport (May 14, 2008), Tropical Storm Fay making landfall in Louisiana (August 22, 2008), and two hurricanes making landfall in Louisiana, Hurricane Gustav (September 1, 2008) and Hurricane Ike (September 13, 2008). Hurricanes Gustav and Ike caused 41 dialysis facilities in Louisiana to close for one or more days, with three facilities remaining closed more than three weeks after Gustav's

initial landfall. One facility closed permanently due to storm-related damage. Facilities, patients, and volunteer organizations put their disaster plans into place, with many facilities dialyzing patients one day early to allow patients to leave the area and go to their designated emergency locations. Network 13 remained open for two weekends and set up a system that allowed callers to be connected to an on-call person during evening and early morning hours.

## Kidney Community Emergency Response (KCER) Coalition

The KCER Coalition was formed in January 2006, at the direction of CMS, in an effort to minimize disruption to life-sustaining dialysis and transplant services in the event of an emergency or disaster. The coalition was initiated when Network 7, the ESRD Network for Florida, convened a National Disaster Summit on January 19, 2006. The coalition includes the ESRD Networks; patient and professional organizations; physicians and other practitioners; LDOs; independent dialysis and transplant facilities; hospitals; suppliers; state emergency management agencies: State Survey Agencies; CMS; and other federal agencies including the Food and Drug Administration and the Centers for Disease Control and Prevention.

Through outreach and presentations, a website (www.kcercoalition.com), and technical assistance, the KCER Coalition raises awareness of the special requirements of individuals with kidney failure in terms of emergency and disaster preparedness. Network 7, as the lead for administrative support of the KCER Coalition, worked throughout 2008 to raise public awareness of the critical needs of individuals with kidney failure and the providers that serve them; to develop and promote tools for planning and managing emergency responses; to develop and promote multimedia educational resources; and to test and refine the national response strategy.



Network 7 provided staff support to eight Response Teams, which were tasked with holding one conference call per team every other month, or as needed and resources allowed. The eight teams and their responsibilities were as follows:

- Patient Assistance: Educate patients on preparedness, resources, and financial aid.
- Communication: Provide an e-mail listsery, conference call capabilities, and during emergencies a toll-free helpline.
- Facility and Patient Tracking: Track displaced patients and report on facility open/closed status.

- Federal Response: Educate federal agencies and state partners, and direct federal resources during a disaster response.
- Facility Operations: Assist facilities with preparedness and response.
- Coordination of Staff and Volunteers: Maintain a database of emergency/disaster volunteers.
- Physician Placement and Assistance: Coordinate nephrology expertise for management of dialysis and transplant patients during a large-scale crisis and identify tools needed to assist physicians whose practices have been disrupted by a disaster.
- Pandemic Preparedness: Collaborate with federal/state agencies to continue dialysis and transplant services in the event of a major pandemic.

The 2008 KCER Coalition Summit was held on February 21, 2008, in Baltimore, Maryland, with 120 participants representing 24 states, all ESRD Networks, CMS, dialysis facilities and other health care providers, health departments, emergency management personnel, patient and professional organizations, and federal agencies. During the Summit, Response Team Leaders reported on recent activities, achievements, and future plans and needs. Teams used this opportunity to discuss possible collaboration with other teams to achieve identified goals.

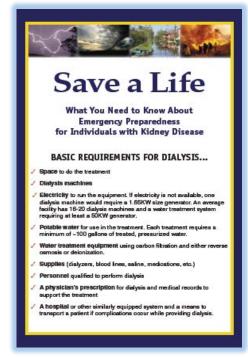
KCER staff, as recognized experts in emergency response and preparedness for the ESRD community, are often called on to speak at national and local meetings. In addition, KCER staff and Coalition members staffed exhibits at a number of meetings and conferences in 2008, including the Annual Meetings of Network 2, 7, and 12, the 9th Annual Southwest Nephrology Conference, the 28th Annual Dialysis Conference, the National Association of Nephrology Technicians Annual Symposium, the National Hurricane Conference, the National Kidney Foundation Spring Clinical Meetings, the American Nephrology Nurses' Association National Symposium, the Renal Support Network's Regional Patient Lifestyle Meetings, the New Jersey Emergency Preparedness Conference, the Florida Governor's Hurricane Conference, the National Association of Transplant Coordinators meeting, the American Association of Kidney Patients Annual Convention, the Dimensions in Dialysis meeting, the National Renal Administrators Association Annual Fall Conference, and the American Society of Nephrology Annual Meeting.

KCER staff and the Response Teams developed a variety of resources and tools in 2008. These resources are posted on the KCER website and are distributed at meetings and exhibits across the country. Among the resources developed during 2008 were:

- "Get Ready!" a disaster preparedness handout for patients
- A "Pandemic Flu Planning Checklist for Individuals with Chronic Kidney Disease and Their Families"
- A set of travel tips titled "Keeping Yourself Safe From Bird Flu"

- A "Save a Life" brochure that educates patients, providers, and emergency management personnel on the special requirements of dialysis patients in an emergency
- A sample Mutual Aid Agreement for dialysis facilities.

Educating stakeholders is vital to ensuring thorough preparedness and efficient emergency/disaster response. In July 2008, KCER mailed 450 *Community Partner Packets* to key stakeholders including state and federal emergency management agencies. The materials were also posted on the KCER website so they could be downloaded and reproduced. The packet included an introduction to the role of the ESRD Networks, patient counts by state, and other resources such as ANNA's *ESRD Briefing Book for State and Federal Policymakers*.



In September 2008, KCER mailed National Preparedness Month packets to the ESRD Networks. In addition to materials contributed by individual Networks, the packets included KCER-developed tools and resources, information on National Emergency Preparedness Education Week For Kidney Patients (September 22–26), and a Pandemic Preparedness Checklist.

## KCER Response Team Exercise

The KCER Coalition hosted an annual mock disaster drill on July 17, 2008. More than 50 people registered for the exercise. Representatives from all of the ESRD Networks and each of the eight Response Teams actively participated. The exercise was set in "Metropolis," a fictional city experiencing extended severe weather, rainfall, and a landslide affecting municipal power and water supplies. Following the exercise, participants were asked to join a debriefing conference call to discuss lessons learned. Several questions and best practices were discussed on the call. For example, participants recommended the development of an online training course that would outline the purpose of disaster exercises. This recommendation was implemented, and an online training course was added to the KCER website.

#### **KCER Technical Assistance**

Any Network can contact Network 7 to request technical assistance. Network 7 staff are also alerted to potential emergencies or disasters through a variety of sources, including CMS, the other ESRD Networks, the news media, and emergency management organizations.

Network 7 provided technical assistance with respect to disaster preparedness, planning, and response to the following Networks in 2008:

- Network 4: assistance with the www.dialysisunits.com website
- Network 5: assistance for threat of Tropical Storm Hanna
- Network 6: assistance for drought, Atlanta tornadoes, and threat of Tropical Storm Hanna

- Network 7: assistance for Tropical Storm Fay, Tropical Storm Hanna, and Hurricane Ike
- Network 8: assistance for tornadoes, Tropical Storm Fay, Hurricane Gustav, and Hurricane Ike
- Network 13: assistance for severe winter weather, tornadoes, severe flooding, Tropical Storm Edouard, Tropical Storm Fay, Hurricane Gustav, and Hurricane Ike
- Network 14: assistance for severe storms, flooding, tornadoes, Hurricane Dolly, Tropical Storm Edouard, Hurricane Gustav, and Hurricane Ike
- Network 15: instructions on using the www.dialysisunits.com website
- Network 17: assistance with severe weather and California wildfires; instructions on www.dialysisunits.com; guidance on disaster exercises
- Network 18: assistance with California wildfires and Los Angeles earthquake; instructions on using the Disaster Patient Activity Report (DPAR).

## KCER 2008 Hurricane Response

In late August, Hurricane Gustav triggered the largest evacuation in U.S. history, with more than 3 million people fleeing the oncoming hurricane. Network 7 served as a central contact and coordination point for Hurricane Gustav, including hosting and facilitating national calls, activating national response teams, and providing updates to KCER members, CMS, the ESRD Networks, and other involved parties. On August 27, 2008, KCER staff offered technical assistance to Networks 8, 13, and 14 in preparation for Hurricane Gustav. For the next two days, KCER staff provided updates on the storm and emergency management preparations. On August 29, Hurricane Gustav became more threatening and KCER hosted the first of many national teleconferences so that the affected Networks, providers, and other stakeholders could collaborate to solve any issues and share information and best practices. These conference calls continued on an almost-daily basis in anticipation of Tropical Storm Hanna, which threatened Networks on the East Coast, and Hurricane Ike, which made landfall in Texas. The daily calls encouraged information sharing and problem solving and provided critical status information for the KCER website, patient and provider websites and hotlines, and key stakeholders.

Hurricane Ike, which made landfall in Galveston, Texas, on September 13, was the third most destructive hurricane to ever have hit the United States. KCER offered technical assistance and resources to Network 14 and TEEC and held national conference calls with stakeholders to assist in locating evacuated Texas patients.

## **Beneficiary Protection and Advocacy**

## Complaints, Grievances, and Involuntary Discharges

The ESRD Networks are charged with informing patients about the procedures used to file complaints and grievances, and with taking the steps necessary to resolve patient complaints and grievances. The authority to do so is outlined in Section 1881(c)(2)(D) of the Social Security Act, as amended, as implemented in CMS regulations at 42 CFR §405.2112(g). In addition, Section 6219(b) of the Omnibus Budget Reconciliation Act of 1989 amended Section 1881(c) of the Social Security Act to apply §1160 ("Prohibition against Disclosure of Information") and §1157 ("Limitation on Liability") of the Act to the ESRD Networks. The Networks also play a role in monitoring and resolving involuntary patient discharges.

The 1976 ESRD Conditions for Coverage (CfCs) provide the framework for summarizing 2008 data on complaints and grievances for the purposes of the present report (see 42 CFR §405.2138; Figure 24). Revised ESRD CfCs were approved on April 15, 2008, and became effective on October 14, 2008. The 2008 CfCs present more detailed regulatory language with regard to complaints, grievances, and involuntary discharges (see §494.70 and §494.180; Figure 24).

Responding to patients who have concerns about quality of care, or about access to ESRD services or rehabilitation, is a high priority for the Networks. CMS encourages Networks to resolve all complaints and grievances at the facility level. As appropriate, Networks implement educational programs to assist the staff of dialysis facilities in addressing difficult situations. The Networks are required to conduct trend analyses of reported situations to detect regional, local, or facility-specific patterns of concern.

The Networks follow CMS policy set forth in the *Medicare ESRD Network Organizations Manual* for evaluating, resolving, and reporting patient complaints and grievances. Each Network has a formal complaint/grievance resolution protocol approved by CMS, which typically includes time frames for referring grievances to CMS and/or the State Survey Agency. State Survey Agencies have the regulatory authority and responsibility to ensure that facilities meet the regulations outlined in the CfCs. As requested by CMS, the Networks assist State Survey Agencies with the investigations of complaints/grievances.

In accordance with applicable statutes, regulations, and CMS policies, the Network maintains confidentiality of: the identity of the patient/complainant/grievant and practitioner; the Network's deliberations; and certain correspondence and documentation related to the Network's investigation and resolution.

Patients with complaints or grievances are encouraged, but not required, to submit them in writing. A patient, family member, friend, patient representative or advocate, facility employee, physician, State Survey Agency, or other interested person can submit a complaint or grievance concerning a dialysis facility, transplantation center, acute care hospital, nursing home, home care provider, or physician to the Network by mail, telephone, or e-mail. Each Network provides a toll-free number for patient use for inquiries, complaints, and grievances. All complaints and grievances received by telephone are documented in the Standard Information Management System (SIMS).

The ESRD Network Program uses the following definitions:

- Inquiry A written, oral, or electronic request from an individual or facility for information, advice, referral, or educational materials that usually does not require problem resolution.
- Complaint A written, oral, or electronic request for assistance initiated by or on behalf of an ESRD patient regarding a concern about an ESRD issue, including but not limited to issues related to care or treatment, or another concern about a dialysis facility or transplantation center.
- **Grievance** A written, oral, or electronic request for a formal investigation of a complaint, or a serious complaint involving a facility/center or a physician or other practitioner.

## **Complaint Process**

Once a complaint is received, the Network determines the appropriate next steps. The Network may act as a facilitator/coordinator, directly investigate the concern, or refer the concern to a more appropriate agency or organization. If a referral to an outside agency or organization is required, the Network makes the referral. When the Network investigates a complaint, Network staff can request documentation, interview facility staff, discuss issues with the administration and/or corporate leadership, conduct on-site investigations, and/or use mediation to resolve the complaint. The Network works with the complainant and the facility and/or practitioner to find an acceptable solution for all involved. The Network documents the resolution in writing to the complainant, and contacts the facility and/or practitioner by telephone or in writing regarding the resolution of the case. If the patient is not satisfied with the results of the investigation, the complainant is advised to contact the appropriate CMS Regional Office and/or State Survey Agency.

#### **Grievance Process**

The formal grievance process requires the Network to conduct a complete review and evaluation of the available information, which may require the involvement of a Grievance Committee and/or the MRB. When the facility and/or practitioner are unable to achieve a mutually agreeable resolution with the patient, the Network has the option of referring the matter to the CMS Regional Office. Otherwise, the Network provides a report to the facility and/or practitioner within 60 calendar days of receiving the grievance, offering them an opportunity to submit additional information or comments within 15 calendar days. The Network advises the facility and/or practitioner that a final report will be sent to the complainant. The Network is required to send a letter of acknowledgement at the beginning of the grievance process and a grievance report (findings and recommendations) at the conclusion of the grievance process to all of the involved parties. When problems are identified, the Network requires the facility to develop and carry out an improvement plan to correct the problem(s).

#### Complaints in 2008

A considerable amount of Network staff time and resources is dedicated to responding to complaints. In 2008, the Networks processed 1,868 patient complaints, which is equivalent to a rate of 5.03 complaints per 1,000 prevalent patients. See Table 21 for Network-specific data.

#### Grievances in 2008

The 18 Networks processed 51 formal beneficiary grievances, 13 more than in 2007. Of the 18 Networks, 6 reported no grievances, while the remaining 11 Networks reported from 1 to 12 grievances. See Table 21 for Network-specific data.

## Improving the Classification of Complaints and Grievances in SIMS

**Network 6** launched a project in 2008 to improve classification of complaints and grievances in SIMS to provide the information needed for targeted, proactive interventions. Network 6 developed sub-codes within each broad Area of Concern in SIMS to better pinpoint the focus of a complaint or grievance. A team convened by the Network reviewed six months of calls to identify potential sub-codes and definitions. The Network then tested the sub-codes by having four people independently code six months of calls and comparing the results. The match rate was high, and the definitions needed only fine-tuning before implementation. Network 6 implemented the four-digit sub-coding system on July 1, 2008.

These four-digit codes are entered into the miscellaneous field for all complaints and grievances. By building this directly into SIMS, the Network is able to link sub-codes with patient demographics and facility characteristics to identify trends and solutions.

Based on these results, the Network developed three online training modules for dialysis facility staff: "Boundaries and Professionalism"; "Understanding the Mental Health of our Patients"; and "Building Relationships that Work."

| SIMS Area of Concern               | Network 6 Sub-Code                           |
|------------------------------------|--|
| Transient                          | 1001-Transient Process                       |
| Request for Technical Assistance   | 1202-Agreement of Expectations               |
|                                    | 1208-Assistance Related to Improving<br>Care |
| Disruptive                         | 2402-Inappropriate Communication             |
| Physical Environment               | 9101-Safety                                  |
|                                    | 9102-Climate                                 |
|                                    | 9103-Blood on Surface                        |
|                                    | 9104-Cleanliness                             |
|                                    | 9105-Amenities                               |
| Staff Related                      | 9201-Staff Monitoring                        |
|                                    | 9203-Staff Competency                        |
|                                    | 9204-Policy/Procedure Inconsistency          |
| Treatment Related/ Quality of Care | 9301-Physician Orders                        |
|                                    | 9302-Treatment Times                         |
|                                    | 9303-Care Plan Meetings                      |
|                                    | 9304-Equipment Related                       |
|                                    | 9305-Treatment Options                       |
|                                    | 9306-Delivery of Care                        |

| Patient Transfer/Discharge | 9603-Necessary for Patient's Welfare   |
|----------------------------|--|
|                            | because Facility Can No Longer Meet    |
|                            | Patient's Documented Medical Needs     |
|                            | 9604-Abusive/Disruptive Behavior       |
|                            | 9606-Difficulty with Patient Placement |
| Professional Ethics        | 9701-HIPAA Violations                  |
|                            | 9703-Lack of Professionalism           |
|                            | 9704-Staff Crossing Boundaries         |
| Reimbursement/Financial    | 9801-Transportation                    |
|                            | 9802-Benefits Assistance               |

## **Involuntary Discharges**

Involuntary patient discharges continue to present substantial challenges for the Networks. In an effort to respond to these challenges, the ESRD community initiated a national, multi-year effort to educate and provide resources to dialysis facilities to help them cope effectively with conflicts between patients and care providers. This national initiative, which began in 2001 with surveys of patients who were discharged involuntarily, served as the foundation for the larger-scale Decreasing Dialysis Patient-Provider Conflict (DPC) Project. The Project is credited with the development of a DPC taxonomy, manual, and toolkit that were distributed to the ESRD community in 2005.

An increased number of involuntary discharges were reported among many ESRD Networks in 2008, with some Networks reporting two- and three-fold increases compared to 2007. In contrast, **Network 11** reported a nearly 50% decrease in the number of involuntary discharges in this time period. In 2008, 31 patients were involuntarily discharged from Network 11 facilities, down from 60 in 2007. Network 11 invested many hours working with providers to address difficult patient situations and to prevent involuntary patient discharge for noncompliance. Of 198 calls from facilities for reasons that could potentially lead to involuntary discharge (noncompliance and disruptive or abusive behavior), only 31 (16% of contacts) led to involuntary discharges. Network 11 encouraged dialysis facility staff to call and discuss difficult patient situations before they escalate to the point of discharge, and to use the DPC resources to manage conflict. Although not all discharges can be averted, ERSD Network personnel can serve an important role in helping dialysis facilities remedy difficulty situations with patients in order to prevent involuntary discharges.

#### Barriers to Outpatient Dialysis Collaborative Project

In 2006, CMS funded the Barriers to Outpatient Dialysis Placement Project under the direction of Networks 9/10. Eight ESRD Networks (1, 9, 10, 11, 14, 15, 16, and 18) participated in a three-month pilot project from January to March 2007. The participating Networks completed an Admission Form for each call related to barriers to placement and a Discharge Form for each call related to involuntary discharges. Even though funding for the Barriers Project ended in 2007, many Networks agreed to continue the data collection effort. Twelve Networks (1, 5, 6, 9, 10, 11, 12, 13, 14, 15, 16, and 18) used the Admissions and Discharge Forms in calendar year 2008 as a way to standardize information about involuntary discharge and placement barriers.

In 2008, 95 Admission Forms were completed by seven of the participating Networks; the other Networks did not receive calls for placement assistance. The category most often reported as a

barrier to outpatient placement was behavior (primarily nonadherence, followed by verbal/written abuse). The demographics of patients who had difficulty locating placement revealed disparities, with higher than expected percentages for male patients, patients in the 18–44 year age group, and patients identified as "Black or African American."

In 2008, 300 Discharge Forms were completed by the Networks for calls related to patient discharges. Noncompliance with treatment was the most frequently identified reason for discharge, followed by verbal/written threats. A review of patient demographics showed disproportionately high discharge rates for male patients, patients in the 18–44 year age group, and patients identified as "Black or African American."

## Educational Efforts to Decrease Involuntary Discharge

With the implementation of the new CfCs in October 2008, the Networks engaged in educational efforts to inform dialysis facilities about the new regulatory language with regard to involuntary discharge. Several Networks posted information on their websites or distributed resource materials directly to dialysis facilities. For example, **Network 16** produced a document titled "Notifying the Network of Involuntary Discharges and Transfers" to assist dialysis facilities in complying with the new regulations. **Network 12** developed and distributed a "Guide to Care Agreements" booklet that provided DPC-related information to help facilities work more effectively with patients in resolving complaints and grievances that could result in involuntary discharges. The Network also developed a patient brochure on complaints and grievances; implemented an internal process to assist facilities and hospitals when placing involuntarily discharged patients; and provided an overview of the new CfC guideline on involuntary discharge. Continued educational efforts are needed to inform all members of the ESRD patient and provider communities.

#### **Recommendations for Sanctions**

Section §1881(c)(3) of the Social Security Act requires the Networks to recommend sanctions to CMS for dialysis facilities and transplantation centers that fail to consistently cooperate with Network goals and improvement plans. Prior to recommending sanctions, the Networks follow a series of protocols as laid out in CMS policy and procedures. These protocols include providing technical assistance and making on-site visits to help low performers improve their quality of patient care.

**Networks 3, 7,** and **11** each recommended sanctions for one ESRD facility after efforts to assist the facility did not result in the expected change in performance and the facility continued to fail in meeting Network goals.

Upon recommendation of the Medical Review Board (MRB) and the Board of the Trustees, a sanction recommendation was forwarded by **Network 3** to the CMS New York Regional Office for one dialysis facility.

In March 2008, the **Network 7** MRB unanimously decided to recommend that CMS sanction a dialysis facility in the Network area. The Network first monitored this facility as part of the 2004 Hemodialysis Adequacy Project. In April 2008, the facility was surveyed by the State Survey Agency, the Agency for Health Care Administration, resulting in a designation of Immediate Jeopardy. Network QI staff and MRB members conducted a 90-day follow-up visit on June 10, 2008. Based

on visit findings, the MRB decided to continue the sanction recommendation and schedule another visit by the same Network staff and MRB members in three months. On September 17, 2008, the Network QI staff and MRB conducted the second 90-day follow-up visit to the facility. At the MRB meeting on September 24, 2008, the Board decided to move forward with a facility sanction and notify the Agency for Health Care Administration and Network 7's CMS Project Officer. Documentation was submitted to CMS on November 26, 2008.

An Administrative Law Judge upheld a sanction recommended by **Network 11**. CMS imposed the sanction, and the dialysis facility used both the informal hearing and Administrative Law Judge appeal processes.

These sanctions and the resulting activities are evidence of the Networks' commitment to quality care. The Networks follow the guidelines stipulated by their Medicare contract to ensure that the activities of facilities in their Network areas are monitored and that facilities provide quality care and work at improving patient care as recommended.

## **Recommendations for Additional Facilities**

Over the years, the number of dialysis facilities in some regions has increased sharply. Despite this increase, many Networks have recommended that CMS pay special attention to areas of particular need, including the treatment of dialysis patients with behavioral problems who have been involuntarily discharged from dialysis facilities. The Networks have strongly urged CMS to study these issues and provide specialized assistance to address identified needs. Several Network included recommendations for CMS in their Annual Reports:

**Network 1:** "The increasing number of challenging or disruptive patients requires unique staff communication and interpersonal skills. Consideration, by CMS, of 'unique needs' dialysis clinics with additional provider reimbursement, to allow for a different staff to patient ratio, would reduce the number of patients experiencing an involuntary discharge from dialysis units."

**Network 6:** "It is our recommendation that CMS ... identify a solution that will provide quality, alternative care for the patient that has been previously involuntarily discharged.... A need has also been identified for outpatient facilities to care for the sub-acute dialysis patients who have special needs such as wound and tracheotomy care."

**Network 8:** "A host of problems are encountered by ESRD patients who reside in long term care facilities.... These tend to be the most fragile of patients, and the thrice-weekly shuttling between the nursing home and dialysis facility represents significant costs, increased opportunities for care transition failures, and inter-organizational conflict over how to appropriately assign resources to the special care needs of these individuals. We encourage CMS to undertake an evaluation to determine whether or not cost savings from elimination of transportation charges would permit a revenue neutral augmentation of the dialysis reimbursement rate for care rendered in [long term care facilities]."

**Network 13:** "The Network continues to see the need for two types of 'special service' facilities that can be adequately staffed and equipped to provide services to subsets of the Medicare patient population with needs that exceed services provided at a typical chronic facility for the general dialysis population. These are: (1) a facility for patients labeled disruptive and discharged from the

chronic facilities without access to another chronic facility. This type of facility would provide services to patients with a history of aggression, mental illness, or substance abuse; and (2) a facility for those dialysis patients having physical requirements (e.g., ventilator-dependent, morbidly obese, antibiotic-resistant infections), or other such needs which require services that typical chronic facilities for the general dialysis population are unable to provide."

In addition to these general recommendations, two Networks made specific recommendations for new facilities:

**Network 11:** "In 2008, Network 11 has been working with a patient, a hospital, two Regional Offices of CMS, Central Office of CMS, and the State Survey Agency on a Special Purpose Dialysis Facility application. The hospital is willing to apply for Medicare certification to dialyze patients with special needs, and Network 11 supports this application."

Network 14: "In 2008, as occurred in 2005, hurricanes caused evacuations of large numbers of dialysis patients from coastal areas into regions with insufficient dialysis surge capacity. The Network recommended and both the Texas Department of State Health Services and CMS approved 17 facilities as Special Purpose Dialysis Facilities that were awaiting initial CMS certification survey. ... The Network recommends that all pending facilities be given priority for certification in regions that are State of Texas evacuation Hub Cities or regions where a medical special needs shelter is operated to increase the surge capacity in these areas. The Network continues to recommend that CMS foster the establishment of special needs dialysis facilities in the major metropolitan areas to serve displaced patients that require chronic dialysis yet do not have a chronic provider. It is anticipated that these special needs facilities would require at least the following special services to meet the needs of this increasing population of patients: security guards and metal detectors; social workers on staff whenever patients are dialyzing; registered nurses on staff whenever patients are dialyzing; lower patient care staff to patient ratio; higher hourly pay rate for all staff; high risk/hazardous pay; and psychological counseling on site."

#### FIGURE 24

# Selected Regulatory Language from the 1976 and 2008 ESRD Conditions for Coverage

## 1976 ESRD Conditions for Coverage

## §405.2138 Condition: Patients' rights and responsibilities.

- (b) Standard: participation in planning. All patients treated in the facility:
  - (2) Are transferred or discharged only for medical reasons or for the patient's welfare or that of other patients, or for nonpayment of fees (except as prohibited by title XVIII of the Social Security Act), and are given advance notice to ensure orderly transfer or discharge.
- (e) Standard: grievance mechanism. All patients are encouraged and assisted to understand and exercise their rights. Grievances and recommended changes in policies and services may be addressed to facility staff, administration, the network organization, and agencies or regulatory bodies with jurisdiction over the facility, through any representative of the patient's choice, without restraint or interference, and without fear of discrimination or reprisal. (42 CFR 405.2138)

## 2008 ESRD Conditions for Coverage

## §494.70 Condition: Patients' rights.

The dialysis facility must inform patients (or their representatives) of their rights (including their privacy rights) and responsibilities when they begin their treatment and must protect and provide for the exercise of those rights.

- (a) Standard: Patients' rights. The patient has the right to-
  - (14) Be informed of the facility's internal grievance process;
  - (15) Be informed of external grievance mechanisms and processes, including how to contact the ESRD Network and the State survey agency;
  - (16) Be informed of his or her right to file internal grievances or external grievances or both without reprisal or denial of services; and
  - (17) Be informed that he or she may file internal or external grievances, personally, anonymously or through a representative of the patient's choosing.
- (b) Standard: Right to be informed regarding the facility's discharge and transfer policies. The patient has the right to—
  - (1) Be informed of the facility's policies for transfer, routine or involuntary discharge, and discontinuation of services to patients; and
  - (2) Receive written notice 30 days in advance of an involuntary discharge, after the facility follows the involuntary discharge procedures described in § 494.180(f)(4). In the case of immediate threats to the health and safety of others, an abbreviated discharge procedure may be allowed.
- (c) *Standard: Posting of rights.* The dialysis facility must prominently display a copy of the patient's rights in the facility, including the current State agency and ESRD network mailing addresses and telephone complaint numbers, where it can be easily seen and read by patients.

## §494.180 Condition: Governance.

- ... (f) Standard: Involuntary discharge and transfer policies and procedures. The governing body must ensure that all staff follow the facility's patient discharge and transfer policies and procedures. The medical director ensures that no patient is discharged or transferred from the facility unless—
  - (1) The patient or payer no longer reimburses the facility for the ordered services;
  - (2) The facility ceases to operate;
  - (3) The transfer is necessary for the patient's welfare because the facility can no longer meet the patient's documented medical needs; or
  - (4) The facility has reassessed the patient and determined that the patient's behavior is disruptive and abusive to the extent that the delivery of care to the patient or the ability of the facility to operate effectively is seriously impaired, in which case the medical director ensures that the patient's interdisciplinary team—
    - (i) Documents the reassessments, ongoing problem(s), and efforts made to resolve the problem(s), and enters this documentation into the patient's medical record;
    - (ii) Provides the patient and the local ESRD Network with a 30-day notice of the planned discharge;
    - (iii) Obtains a written physician's order that must be signed by both the medical director and the patient's attending physician concurring with the patient's discharge or transfer from the facility;
    - (iv) Contacts another facility, attempts to place the patient there, and documents that effort; and
    - (v) Notifies the State survey agency of the involuntary transfer or discharge.
  - (5) In the case of immediate severe threats to the health and safety of others, the facility may utilize an abbreviated involuntary discharge procedure.

## Looking to the Future

This section summarizes significant findings from the present report and suggests future directions for the ESRD Network Program based on these findings.

## **ESRD** Incidence and Dialysis Prevalence

While the number of dialysis facilities in the U.S. increased from 5,118 in 2007 to 5,408 in 2008 (Figure 2), the rate of newly occurring ESRD cases in the same time frame remained steady at 362 per million population in 2007 and 2008 (Table 3).

From 2003 to 2006, the incidence of ESRD as reported by the Networks increased steadily from year to year; however, a slower rate of change is evident for 2006 to 2008 (Figure 3). Improvements in treatment of chronic kidney disease (CKD) and other diseases that continue to put people at risk of ESRD, including diabetes and hypertension, may have had an effect on decelerating the historic rising trend in ESRD incidence. Of note, there was considerable variation in ESRD incidence across Networks in 2008, from 229 patients per million population (Network 16) to 441 per million population (Network 8).

The prevalent dialysis population increased steadily from 2003 to 2008 (Figure 4). Reasons for this may have included survival benefits from improved care for ESRD patients as well as improvements in the care of co-morbid conditions. Data released by the United States Renal Data System reveal lower mortality rates among ESRD patients across modalities and treatment duration as compared to previous years.<sup>22</sup> This lower mortality rate finding corroborates the prevalence trends highlighted in this report.

The markedly high ESRD incidence and prevalence in the African American population relative to their representation in the population as a whole (Tables 6, 10, and 22) has not been fully explained. High rates of hypertension and diabetes in this population are among the contributing factors, but more research is needed to explore whether differences in access to or quality of CKD care also contribute to relatively high ESRD rates among people identified as African American. Of note, the "Black or African American" and "American Indian or Alaska Native" categories had the smallest proportions of ESRD patients receiving transplants in 2008.

## Fistula First Breakthrough Initiative

Since 2002, data from all facilities participating in the Fistula First Initiative reveal that the national rate of AVF use among hemodialysis patients has increased by an average of 8.1% a year (Figure 14).

<sup>&</sup>lt;sup>21</sup> United States Renal Data System. Incidence of Reported ESRD. In: United States Renal Data System. *United States Renal Data System 2008 Annual Data Report: Atlas of End-stage Renal Disease in the United States. Vol. III: Reference Tables.* Bethesda, MD: National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Disease; 2009:429-452.

<sup>&</sup>lt;sup>22</sup> United States Renal Data System. Chapter 6: Mortality and Morbidity. In: United States Renal Data System. *United States Renal Data System 2008 Annual Data Report: Atlas of End-stage Renal Disease in the United States. Vol. II.* Bethesda, MD: National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Disease; 2009:269-280.

In 2008, 51.6% of prevalent in-center and home hemodialysis patients used an AVF, which represents a 19.2 percentage point increase since 2002. The steady improvement in the national rate of AVF use is due in part to interventions implemented by the ESRD Networks. Continued efforts are needed by the Networks to achieve the CMS ESRD "Breakthrough Initiative" goal of at least 66% fistula use among prevalent hemodialysis patients.

## **CPM** and Elab Projects

Clinical performance monitoring of anemia management is likely to undergo some updates in the coming years. In 2007, the Food and Drug Administration issued a black box warning for erythropoiesis-stimulating agents after research was published suggesting a link between adverse health outcomes and hemoglobin concentrations  $\geq 13$  g/dL. Following issuance of the FDA warning, the National Kidney Foundation Kidney Disease Outcomes Quality Initiative (KDOQI) revised its anemia management guidelines and recommended a new target hemoglobin concentration for dialysis patients of 11 g/dL–12 g/dL. As a result of the black box warning and changes in the KDOQI guidelines, the percentage of dialysis patients with hemoglobin  $\geq 13$  g/dL has begun to decline and the percentage of patients with a hemoglobin concentration in the targeted range (11 g/dL–12 g/dL) is increasing. In the future, anemia management efforts are likely to focus on monitoring patients' serum hemoglobin levels to prevent them from exceeding 12 g/dL.

According to Elab Project data, 41% of all adult hemodialysis patients, 34% of adult peritoneal dialysis patients, and 29% of pediatric dialysis patients had mean hemoglobin concentrations in the 11 g/dL–12 g/dL range in the fourth quarter of 2008. This represented a 9 percentage point increase for adult hemodialysis patients relative to the fourth quarter of 2006, a 4 percentage point increase for adult peritoneal dialysis patients, and a 2 percentage point increase for pediatric dialysis patients.

### Vocational Rehabilitation

The enabling federal legislation that established Medicare's ESRD Network Program in 1986 framed the program with a rehabilitation focus, not strictly as a clinical quality improvement program. The program was intended to help ensure that not only would ESRD patients be able to afford and receive good quality clinical treatment and care, but also that they would be supported in maintaining independent and fully functioning lifestyles.

There was a three-fold variation across the Networks in the reported employment rates of ESRD patients, with the highest rates (28%–29%) reported by Networks 3, 15, and 16 (Table 20). Further, there was marked variation across Networks in the rate of dialysis facilities that were open after 5:00 PM; Networks 1, 2, and 16 had the highest rates (36%–50%). Access to dialysis after 5:00 PM can

<sup>23</sup> Singh AK, Szczech L, Tang KL, Barnhart H, Sapp S, Wolfson M, Reddan D; CHOIR Investigators. Correction of anemia with epoetin alfa in chronic kidney disease. *N Engl J Med.* 2006;355(20):2085-98.

<sup>&</sup>lt;sup>24</sup> National Kidney Foundation Kidney Disease Outcomes Quality Initiative. KDOQI Clinical Practice Guideline and Clinical Practice Recommendations for Anemia in Chronic Kidney Disease: 2007 Update of Hemoglobin Target. CPG AND CPR 2.1 Hemoglobin Target. Available at: http://www.kidney.org/professionals/KDOQI/guidelines\_anemiaUP/guide1.htm

help patients schedule treatment in ways that are flexible and enabling of other meaningful personal pursuits such maintaining employment or going to school. However, given the findings reported in Table 20, additional work is needed to understand the barriers to and facilitators of patient employment beyond the availability of dialysis treatment after 5:00 PM.

## **Home Dialysis**

A final trend is an increase in use of home hemodialysis, with a 23% increase from 2007 to 2008 (Table 13). The increase in home hemodialysis resulted in part from the development of home hemodialysis equipment that is more reliable, space-efficient, and user-friendly. In addition, large dialysis organizations have become more active in promoting this treatment modality. In the future, more dialysis patients are expected to select home hemodialysis as their preferred treatment modality.

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TABLE 1

Prevalent Dialysis Patients, Dialysis Facilities, and Full-Time Equivalent (FTE) Network Staff
Assigned to Core Contract Activities, by Function, 2008

| Network | Number of Dialysis<br>Patients as of<br>December 31, 2008 | Number of Dialysis<br>Facilities in Network<br>Area as of<br>December 31, 2008 | Administrative<br>FTEs | Quality<br>Improvement<br>FTEs | Data<br>FTEs | Patient<br>Services<br>FTEs | Non-Core<br>Contract | Total<br>FTEs |
|---------|---|--|------------------------|--------------------------------|--------------|-----------------------------|----------------------|---------------|
| 1       | 11,966  | 166  | 2.60                   | 2.60                           | 2.80         | 2.30                        | 0                    | 10.30         |
| 2       | 24,214  | 237  | 2.00                   | 2.50                           | 4.00         | 1.60                        | 4.00                 | 14.10         |
| 3       | 15,404  | 166  | 1.75                   | 2.40                           | 2.70         | 1.50                        | 0                    | 8.35          |
| 4       | 16,226  | 265  | 3.00                   | 1.22                           | 4.00         | 1.52                        | 0                    | 9.74          |
| 5       | 21,529  | 312  | 2.80                   | 3.40                           | 3.10         | 2.50                        | 0                    | 11.80         |
| 6       | 35,650  | 547  | 2.00                   | 3.10                           | 2.90         | 2.00                        | 0                    | 10.00         |
| 7       | 21,272  | 350  | 3.17                   | 1.98                           | 2.11         | 3.00                        | 10.16                | 20.42         |
| 8       | 21,077  | 339  | 1.50                   | 3.50                           | 3.50         | 1.50                        | 0                    | 10.00         |
| 9*      | 26,268  | 472  | 4.00                   | 4.00                           | 6.00         | 4.00                        | 0                    | 18.00         |
| 10*     | 15,659  | 218  | 4.00                   | 4.00                           | 0.00         | 4.00                        | 0                    | 10.00         |
| 11      | 22,726  | 402  | 1.50                   | 2.85                           | 4.00         | 3.00                        | 0.65                 | 12.00         |
| 12      | 13,362  | 266  | 2.85                   | 1.95                           | 2.70         | 1.25                        | 0                    | 8.75          |
| 13      | 14,799  | 277  | 1.70                   | 3.25                           | 2.85         | 2.70                        | 0                    | 10.50         |
| 14      | 33,933  | 453  | 2.00                   | 3.40                           | 4.00         | 2.70                        | 0                    | 12.10         |
| 15      | 17,276  | 273  | 3.20                   | 3.50                           | 3.40         | 2.00                        | 0                    | 12.10         |
| 16      | 10,061  | 147  | 2.00                   | 1.44                           | 2.64         | 1.92                        | 0                    | 8.00          |
| 17      | 19,771  | 204  | 2.00                   | 2.50                           | 2.00         | 1.50                        | 0                    | 8.00          |
| 18      | 30,547  | 314  | 2.50                   | 3.00                           | 4.00         | 3.00                        | 0                    | 12.50         |
| TOTAL   | 371,740   | 5,408  | 40.57                  | 46.59                          | 56.70        | 37.99                       | 14.81                | 196.66        |
| Mean    | 20,652  | 300  | 2.39                   | 2.74                           | 3.34         | 2.23                        | 0.82                 | 11.57         |

\*Since 1996, the contracts for Networks 9 and 10 have been awarded to the same organization; some staff members and costs are divided between the two contracts.

TABLE 2

Data Forms Processed in Calendar Year 2008

| Network | Medical Evidence Report<br>(Form CMS-2728) | Death Notification<br>(Form CMS-2746) | Total   |
|---------|--|---------------------------------------|---------|
| 1       | 4,106                                      | 2,826                                 | 6,932   |
| 2       | 7,647                                      | 4,976                                 | 12,623  |
| 3       | 5,387                                      | 3,781                                 | 9,168   |
| 4       | 5,709                                      | 4,351                                 | 10,060  |
| 5       | 6,854                                      | 4,421                                 | 11,275  |
| 6       | 8,952                                      | 5,673                                 | 14,625  |
| 7       | 7,955                                      | 5,405                                 | 13,360  |
| 8       | 6,488                                      | 4,430                                 | 10,918  |
| 9       | 9,351                                      | 6,723                                 | 16,074  |
| 10      | 5,360                                      | 3,534                                 | 8,894   |
| 11      | 8,231                                      | 5,746                                 | 13,977  |
| 12      | 4,693                                      | 3,345                                 | 8,038   |
| 13      | 5,046                                      | 3,466                                 | 8,512   |
| 14      | 9,384                                      | 6,224                                 | 15,608  |
| 15      | 5,533                                      | 3,365                                 | 8,898   |
| 16      | 3,403                                      | 2,286                                 | 5,689   |
| 17      | 5,611 3,46                                 |                                       | 9,079   |
| 18      | 9,782                                      | 5,651                                 | 15,433  |
| TOTAL   | 119,492                                    | 79,671                                | 199,163 |

TABLE 3
Incident ESRD Patients, 2008, and ESRD Incidence per Million Population,
2008 Compared with 2007

| Network | Number of Incident<br>Patients, Calendar Year<br>2008 | Population of<br>Network Area<br>2008 | Incidence per<br>Million Population<br>2008 | Incidence per<br>Million Population<br>2007 |  |
|---------|---|---------------------------------------|---|---|--|
| 1       | 3,852   | 14,303,542                            | 269   | 262   |  |
| 2       | 7,265   | 19,490,297                            | 373   | 378   |  |
| 3       | 4,985   | 12,745,310                            | 391   | 392   |  |
| 4       | 5,286   | 13,321,371                            | 397   | 412   |  |
| 5       | 6,488   | 15,808,987                            | 410   | 408   |  |
| 6       | 9,322   | 23,387,958                            | 399   | 401   |  |
| 7       | 7,167   | 18,328,340                            | 391   | 386   |  |
| 8       | 6,093   | 13,815,406                            | 441   | 432   |  |
| 9       | 8,672   | 22,131,947                            | 392   | 393   |  |
| 10      | 4,863   | 12,901,563                            | 377   | 379   |  |
| 11      | 7,482   | 22,297,457                            | 336   | 330   |  |
| 12      | 4,163   | 13,499,726                            | 308   | 312   |  |
| 13      | 4,685   | 10,908,547                            | 429   | 429   |  |
| 14      | 9,125   | 24,326,974                            | 375   | 370   |  |
| 15      | 5,182   | 19,293,251                            | 269   | 264   |  |
| 16      | 3,094   | 13,516,833                            | 229   | 239   |  |
| 17      | 5,368   | 15,356,754                            | 350   | 344   |  |
| 18      | 8,697   | 23,015,544                            | 378   | 375   |  |
| TOTAL   | 111,789   | 308,449,807                           | 362   | 362   |  |

NOTE: Reporting based on data recorded on Form CMS-2728.

SOURCES: Number of incident patients 2008: Networks 1–18 2008 Summary Annual Report Data Overview Forms. Population data for 50 U.S. states and Puerto Rico: U.S. Census Bureau Population Estimates for July 2008, retrieved from: http://factfinder.census.gov. Population data for American Samoa, Guam, and the Northern Mariana Islands: Network 17 Annual Report 2008. Population Data for Virgin Islands: Network 3 Annual Report 2007. Incidence per million population 2007: ESRD Network Organization Program 2007 Summary Annual Report.

TABLE 4

Incident ESRD Patients by Age Group (in Years), Calendar Year 2008

| Network    | 0–19  | 20–29 | 30–39 | 40–49  | 50–59  | 60–69  | 70–79  | ≥ 80   | Total Number of<br>Incident ESRD<br>Patients,<br>Calendar Year 2008 |
|------------|-------|-------|-------|--------|--------|--------|--------|--------|---|
| 1          | 41    | 67    | 140   | 367    | 646    | 875    | 883    | 833    | 3,852   |
| 2          | 80    | 175   | 335   | 708    | 1,288  | 1,676  | 1,627  | 1,376  | 7,265   |
| 3          | 31    | 96    | 209   | 448    | 913    | 1,197  | 1,168  | 923    | 4,985   |
| 4          | 68    | 103   | 190   | 481    | 898    | 1,220  | 1,262  | 1,064  | 5,286   |
| 5          | 54    | 143   | 334   | 694    | 1,350  | 1,543  | 1,504  | 866    | 6,488   |
| 6          | 90    | 258   | 637   | 1,170  | 1,982  | 2,287  | 1,934  | 964    | 9,322   |
| 7          | 72    | 152   | 330   | 714    | 1,239  | 1,590  | 1,717  | 1,353  | 7,167   |
| 8          | 66    | 157   | 383   | 758    | 1,292  | 1,505  | 1,282  | 650    | 6,093   |
| 9          | 70    | 167   | 405   | 841    | 1,562  | 2,078  | 2,030  | 1,519  | 8,672   |
| 10         | 40    | 120   | 268   | 482    | 932    | 1,155  | 1,071  | 795    | 4,863   |
| 11         | 84    | 151   | 338   | 706    | 1,327  | 1,758  | 1,785  | 1,333  | 7,482   |
| 12         | 63    | 94    | 188   | 393    | 801    | 990    | 972    | 662    | 4,163   |
| 13         | 42    | 117   | 252   | 524    | 993    | 1,130  | 986    | 641    | 4,685   |
| 14         | 117   | 243   | 583   | 1,073  | 2,131  | 2,235  | 1,748  | 995    | 9,125   |
| 15         | 81    | 144   | 278   | 552    | 999    | 1,310  | 1,147  | 671    | 5,182   |
| 16         | 46    | 80    | 160   | 285    | 553    | 773    | 710    | 487    | 3,094   |
| 17         | 71    | 142   | 257   | 623    | 1,104  | 1,284  | 1,112  | 775    | 5,368   |
| 18         | 133   | 278   | 437   | 900    | 1,733  | 1,942  | 1,860  | 1,414  | 8,697   |
| TOTAL      | 1,249 | 2,687 | 5,724 | 11,719 | 21,743 | 26,548 | 24,798 | 17,321 | 111,789   |
| % of Total | 1.1%  | 2.4%  | 5.1%  | 10.5%  | 19.5%  | 23.7%  | 22.2%  | 15.5%  | 100%  |

NOTE: Reporting based on data recorded on Form CMS-2728.

TABLE 5

Incident ESRD Patients by Gender, Calendar Year 2008, and Estimated Gender Distribution of U.S. Population\*, July 2008

| Network  | Male   | Female | Unknown | Total Number of<br>Incident Patients,<br>Calendar Year 2008 | Population of<br>Network Area, 2008 |
|--|--------|--------|---------|---|-------------------------------------|
| 1  | 2,286  | 1,566  | 0       | 3,852   | 14,303,542                          |
| 2  | 4,229  | 3,036  | 0       | 7,265   | 19,490,297                          |
| 3  | 2,904  | 2,081  | 0       | 4,985   | 12,745,310                          |
| 4  | 3,032  | 2,254  | 0       | 5,286   | 13,321,371                          |
| 5  | 3,631  | 2,857  | 0       | 6,488   | 15,808,987                          |
| 6  | 5,058  | 4,264  | 0       | 9,322   | 23,387,958                          |
| 7  | 4,288  | 2,875  | 4       | 7,167   | 18,328,340                          |
| 8  | 3,219  | 2,874  | 0       | 6,093   | 13,815,406                          |
| 9  | 4,795  | 3,877  | 0       | 8,672   | 22,131,947                          |
| 10   | 2,772  | 2,091  | 0       | 4,863   | 12,901,563                          |
| 11   | 4,232  | 3,250  | 0       | 7,482   | 22,297,457                          |
| 12   | 2,349  | 1,814  | 0       | 4,163   | 13,499,726                          |
| 13   | 2,570  | 2,115  | 0       | 4,685   | 10,908,547                          |
| 14   | 4,892  | 4,224  | 9       | 9,125   | 24,326,974                          |
| 15   | 3,034  | 2,148  | 0       | 5,182   | 19,293,251                          |
| 16   | 1,787  | 1,307  | 0       | 3,094   | 13,516,833                          |
| 17   | 3,029  | 2,339  | 0       | 5,368   | 15,356,754                          |
| 18   | 5,009  | 3,688  | 0       | 8,697   | 23,015,544                          |
| TOTAL  | 63,116 | 48,660 | 13      | 111,789   | 308,449,807                         |
| % of Total                                       | 56.5%  | 43.5%  | 0.0%    | 100%  | <u> </u>                            |
| Estimated % of<br>U.S. Population*,<br>July 2008 | 49.3%  | 50.7%  | 0.0%    | 100%  | _                                   |

\*Based on data for the 50 U.S. states and Washington, DC.

NOTE: Reporting based on data recorded on Form CMS-2728.

SOURCES: Patient data: Networks 1–18 2008 Summary Annual Report Data Overview Forms. Population data for 50 U.S. states and Puerto Rico: U.S. Census Bureau Population Estimates for July 2008, retrieved from: http://factfinder.census.gov. Population data for American Samoa, Guam, and the Northern Mariana Islands: Network 17 Annual Report 2008. Population Data for Virgin Islands: Network 3 Annual Report 2007.

TABLE 6

Incident ESRD Patients by Reported Race, Calender Year 2008, and Estimated Racial Distribution of U.S. Population\*, July 2008

| Network                                    | Black or<br>African<br>American | White  | Asian and Native<br>Hawaiian or<br>Other Pacific<br>Islander | American Indian<br>or Alaska Native | Two or More<br>Races | Missing and<br>Unknown | Total Number of<br>Incident ESRD<br>Patients, Calendar<br>Year 2008 | Population of<br>Network Area,<br>2008 |
|--|---------------------------------|--------|--|-------------------------------------|----------------------|------------------------|---|--|
| 1  | 546                             | 3,180  | 103  | 3                                   | 20                   | 0                      | 3,852   | 14,303,542                             |
| 2  | 2,186                           | 4,431  | 360  | 22                                  | 98                   | 168                    | 7,265   | 19,490,297                             |
| 3  | 1,299                           | 3,433  | 148  | 5                                   | 94                   | 6                      | 4,985   | 12,745,310                             |
| 4  | 1,221                           | 3,970  | 80   | 5                                   | 10                   | 0                      | 5,286   | 13,321,371                             |
| 5  | 3,122                           | 3,103  | 160  | 17                                  | 29                   | 57                     | 6,488   | 15,808,987                             |
| 6  | 5,134                           | 4,001  | 98   | 73                                  | 16                   | 0                      | 9,322   | 23,387,958                             |
| 7  | 2,130                           | 4,823  | 126  | 12                                  | 30                   | 46                     | 7,167   | 18,328,340                             |
| 8  | 3,001                           | 3,026  | 31   | 27                                  | 8                    | 0                      | 6,093   | 13,815,406                             |
| 9  | 1,969                           | 6,592  | 44   | 14                                  | 40                   | 13                     | 8,672   | 22,131,947                             |
| 10   | 1,549                           | 3,103  | 152  | 6                                   | 17                   | 36                     | 4,863   | 12,901,563                             |
| 11   | 1,676                           | 5,442  | 137  | 170                                 | 57                   | 0                      | 7,482   | 22,297,457                             |
| 12   | 809                             | 3,256  | 56   | 37                                  | 5                    | 0                      | 4,163   | 13,499,726                             |
| 13   | 1,863                           | 2,575  | 61   | 180                                 | 6                    | 0                      | 4,685   | 10,908,547                             |
| 14   | 2,232                           | 6,533  | 184  | 35                                  | 8                    | 133                    | 9,125   | 24,326,974                             |
| 15   | 445                             | 4,119  | 182  | 422                                 | 14                   | 0                      | 5,182   | 19,293,251                             |
| 16   | 201                             | 2,556  | 228  | 94                                  | 15                   | 0                      | 3,094   | 13,516,833                             |
| 17   | 649                             | 3,144  | 1,466  | 40                                  | 69                   | 0                      | 5,368   | 15,356,754                             |
| 18   | 1,110                           | 6,469  | 1,051  | 25                                  | 42                   | 0                      | 8,697   | 23,015,544                             |
| TOTAL                                      | 31,142                          | 73,756 | 4,667  | 1,187                               | 578                  | 459                    | 111,789   | 308,449,807                            |
| % of Total                                 | 27.9%                           | 66.0%  | 4.2%   | 1.1%                                | 0.5%                 | 0.4%                   | 100%  |  |
| Estimated % of U.S. Population*, July 2008 | 12.9%                           | 79.8%  | 4.6%   | 1.0%                                | 1.7%                 | 0.0%                   | 100%  | _                                      |

\*Based on data for the 50 U.S. states and Washington, DC.

NOTE: Data are compiled by the Networks using Form CMS-2728, which is typically completed by facilities. The form also provides data on ethnicity, defined as "Hispanic or Latino" or "not Hispanic or Latino" (data not shown). Race data are reported here to highlight disproportionate burdens of disease for certain population groups, especially at the national level.

SOURCES: Patient data: Networks 1–18 2008 Summary Annual Report Data Overview Forms. Population data for 50 U.S. states and Puerto Rico: U.S. Census Bureau Population Estimates for July 2008, retrieved from: http://factfinder.census.gov. Population data for American Samoa, Guam, and the Northern Mariana Islands: Network 17 Annual Report 2008. Population Data for Virgin Islands: Network 3 Annual Report 2007.

TABLE 7

Incident ESRD Patients by Primary Diagnosis, Calendar Year 2008

| Network    | Diabetes | Hypertension | Glomerulonephritis | Cystic Kidney<br>Disease | Other* | Unknown | Missing | Total Number of<br>Incident ESRD<br>Patients, Calendar<br>Year 2008 |
|------------|----------|--------------|--------------------|--------------------------|--------|---------|---------|---|
| 1          | 1,493    | 911          | 373                | 141                      | 735    | 199     | 0       | 3,852   |
| 2          | 2,903    | 1,874        | 554                | 196                      | 1,106  | 443     | 189     | 7,265   |
| 3          | 2,466    | 1,223        | 340                | 96                       | 769    | 85      | 6       | 4,985   |
| 4          | 2,253    | 1,331        | 352                | 128                      | 929    | 293     | 0       | 5,286   |
| 5          | 2,640    | 2,065        | 391                | 136                      | 981    | 270     | 5       | 6,488   |
| 6          | 3,980    | 3,028        | 603                | 195                      | 1,172  | 344     | 0       | 9,322   |
| 7          | 2,908    | 2,341        | 440                | 179                      | 1,064  | 177     | 58      | 7,167   |
| 8          | 2,568    | 2,147        | 354                | 127                      | 706    | 191     | 0       | 6,093   |
| 9          | 3,173    | 1,697        | 486                | 190                      | 1,124  | 1,988   | 14      | 8,672   |
| 10         | 1,811    | 1,733        | 272                | 93                       | 584    | 328     | 42      | 4,863   |
| 11         | 2,962    | 1,952        | 547                | 245                      | 1,466  | 310     | 0       | 7,482   |
| 12         | 1,789    | 1,158        | 303                | 117                      | 648    | 146     | 2       | 4,163   |
| 13         | 2,022    | 1,591        | 248                | 103                      | 582    | 139     | 0       | 4,685   |
| 14         | 4,907    | 2,350        | 451                | 150                      | 948    | 174     | 145     | 9,125   |
| 15         | 2,567    | 1,101        | 432                | 136                      | 758    | 188     | 0       | 5,182   |
| 16         | 1,286    | 663          | 300                | 108                      | 564    | 173     | 0       | 3,094   |
| 17         | 2,738    | 1,263        | 409                | 121                      | 652    | 185     | 0       | 5,368   |
| 18         | 4,127    | 2,456        | 522                | 180                      | 976    | 436     | 0       | 8,697   |
| TOTAL      | 48,593   | 30,884       | 7,377              | 2,641                    | 15,764 | 6,069   | 461     | 111,789   |
| % of Total | 43.5%    | 27.6%        | 6.6%               | 2.4%                     | 14.1%  | 5.4%    | 0.4%    | 100%  |

\*Includes "Other" and "Other Urologic."

NOTE: Reporting based on data recorded on Form CMS-2728.

TABLE 8

Prevalent Dialysis Patients by Age Group (in Years), as of December 31, 2008

| Network    | 0–19  | 20–29 | 30–39  | 40–49  | 50–59  | 60–69  | 70–79  | ≥ 80   | Total Number of<br>Dialysis Patients as of<br>December 31, 2008 |
|------------|-------|-------|--------|--------|--------|--------|--------|--------|---|
| 1          | 52    | 239   | 586    | 1,345  | 2,132  | 2,772  | 2,719  | 2,121  | 11,966  |
| 2          | 128   | 529   | 1,327  | 2,983  | 4,917  | 5,883  | 5,041  | 3,406  | 24,214  |
| 3          | 47    | 359   | 816    | 1,805  | 3,119  | 3,968  | 3,252  | 2,038  | 15,404  |
| 4          | 67    | 343   | 875    | 1,879  | 3,214  | 3,767  | 3,520  | 2,561  | 16,226  |
| 5          | 97    | 506   | 1,293  | 2,943  | 4,992  | 5,330  | 4,222  | 2,146  | 21,529  |
| 6          | 145   | 1,003 | 2,800  | 5,294  | 8,489  | 8,948  | 6,288  | 2,683  | 35,650  |
| 7          | 147   | 541   | 1,319  | 2,718  | 4,314  | 4,899  | 4,441  | 2,893  | 21,272  |
| 8          | 97    | 569   | 1,612  | 3,129  | 4,959  | 5,168  | 3,857  | 1,686  | 21,077  |
| 9          | 131   | 567   | 1,575  | 3,238  | 5,538  | 6,188  | 5,601  | 3,430  | 26,268  |
| 10         | 78    | 434   | 997    | 1,813  | 3,298  | 3,765  | 3,306  | 1,968  | 15,659  |
| 11         | 123   | 538   | 1,264  | 2,633  | 4,514  | 5,241  | 4,965  | 3,448  | 22,726  |
| 12         | 81    | 339   | 785    | 1,556  | 2,807  | 3,211  | 2,819  | 1,764  | 13,362  |
| 13         | 107   | 438   | 1,150  | 2,107  | 3,511  | 3,560  | 2,637  | 1,289  | 14,799  |
| 14         | 262   | 902   | 2,297  | 4,735  | 8,435  | 8,722  | 5,940  | 2,640  | 33,933  |
| 15         | 163   | 488   | 1,062  | 2,100  | 3,647  | 4,452  | 3,521  | 1,843  | 17,276  |
| 16         | 81    | 318   | 689    | 1,183  | 2,050  | 2,475  | 1,975  | 1,290  | 10,061  |
| 17         | 89    | 538   | 1,238  | 2,447  | 4,327  | 4,707  | 3,996  | 2,429  | 19,771  |
| 18         | 241   | 1,005 | 1,992  | 3,821  | 6,666  | 7,422  | 6,029  | 3,371  | 30,547  |
| TOTAL      | 2,136 | 9,656 | 23,677 | 47,729 | 80,929 | 90,478 | 74,129 | 43,006 | 371,740   |
| % of Total | 0.6%  | 2.6%  | 6.4%   | 12.8%  | 21.8%  | 24.3%  | 19.9%  | 11.6%  | 100%  |

NOTE: Reporting based on data recorded on Form CMS-2728.

TABLE 9

Prevalent Dialysis Patients by Gender as of December 31, 2008, and Estimated Gender Distribution of U.S. Population, July 2008

| Network  | Male    | Female  | Unknown | Total Number of Dialysis<br>Patients as of December<br>31, 2008 | Population of<br>Network Area |
|--|---------|---------|---------|---|-------------------------------|
| 1  | 6,808   | 5,158   | 0       | 11,966  | 14,303,542                    |
| 2  | 13,685  | 10,529  | 0       | 24,214  | 19,490,297                    |
| 3  | 8,947   | 6,457   | 0       | 15,404  | 12,745,310                    |
| 4  | 9,024   | 7,202   | 0       | 16,226  | 13,321,371                    |
| 5  | 11,903  | 9,626   | 0       | 21,529  | 15,808,987                    |
| 6  | 18,771  | 16,879  | 0       | 35,650  | 23,387,958                    |
| 7  | 12,183  | 9,087   | 2       | 21,272  | 18,328,340                    |
| 8  | 11,037  | 10,040  | 0       | 21,077  | 13,815,406                    |
| 9  | 14,383  | 11,885  | 0       | 26,268  | 22,131,947                    |
| 10   | 8,776   | 6,883   | 0       | 15,659  | 12,901,563                    |
| 11   | 12,616  | 10,110  | 0       | 22,726  | 22,297,457                    |
| 12   | 7,318   | 6,044   | 0       | 13,362  | 13,499,726                    |
| 13   | 7,906   | 6,893   | 0       | 14,799  | 10,908,547                    |
| 14   | 17,893  | 16,036  | 4       | 33,933  | 24,326,974                    |
| 15   | 9,637   | 7,639   | 0       | 17,276  | 19,293,251                    |
| 16   | 5,732   | 4,329   | 0       | 10,061  | 13,516,833                    |
| 17   | 10,791  | 8,980   | 0       | 19,771  | 15,356,754                    |
| 18   | 17,157  | 13,390  | 0       | 30,547  | 23,015,544                    |
| TOTAL  | 204,567 | 167,167 | 6       | 371,740   | 308,449,807                   |
| % of Total                                       | 55.0%   | 45.0%   | 0.0%    | 100%  | <del></del>                   |
| Estimated % of<br>U.S. Population*,<br>July 2008 | 49.3%   | 50.7%   | 0.0%    | 100%  | —                             |

\*Based on data for the 50 U.S. states and Washington, DC.

NOTE: Reporting based on data recorded on Form CMS-2728.

SOURCES: Patient data:Networks 1–18 2008 Summary Annual Report Data Overview Forms. Population data for 50 U.S. states and Puerto Rico: U.S. Census Bureau Population Estimates for July 2008, retrieved from: http://factfinder.census.gov. Population data for American Samoa, Guam, and the Northern Mariana Islands: Network 17 Annual Report 2008. Population Data for Virgin Islands: Network 3 Annual Report 2007.

TABLE 10

Prevalent Dialysis Patients by Reported Race, as of December 31, 2008, and Estimated Racial Distribution of U.S. Population\*, July 2008

| Network  | Black or<br>African<br>American | White   | Asian and Native<br>Hawaiian or<br>Other Pacific<br>Islander | American Indian<br>or Alaska Native | Two or More<br>Races | Missing and<br>Unknown | Total Number of<br>Dialysis Patients as<br>of December 31,<br>2008 | Population of<br>Network Area,<br>2008 |
|--|---------------------------------|---------|--|-------------------------------------|----------------------|------------------------|--|--|
| 1  | 2,440                           | 9,024   | 380  | 68                                  | 54                   | 0                      | 11,966   | 14,303,542                             |
| 2  | 9,759                           | 12,591  | 1,277  | 196                                 | 252                  | 139                    | 24,214   | 19,490,297                             |
| 3  | 5,018                           | 8,548   | 527  | 26                                  | 1,283                | 2                      | 15,404   | 12,745,310                             |
| 4  | 5,709                           | 10,200  | 263  | 19                                  | 35                   | 0                      | 16,226   | 13,321,371                             |
| 5  | 13,178                          | 7,642   | 554  | 46                                  | 61                   | 48                     | 21,529   | 15,808,987                             |
| 6  | 24,127                          | 10,815  | 404  | 256                                 | 48                   | 0                      | 35,650   | 23,387,958                             |
| 7  | 8,716                           | 12,009  | 379  | 51                                  | 89                   | 28                     | 21,272   | 18,328,340                             |
| 8  | 13,041                          | 7,793   | 119  | 102                                 | 22                   | 0                      | 21,077   | 13,815,406                             |
| 9  | 8,837                           | 17,122  | 159  | 32                                  | 96                   | 22                     | 26,268   | 22,131,947                             |
| 10   | 6,528                           | 8,485   | 506  | 29                                  | 59                   | 52                     | 15,659   | 12,901,563                             |
| 11   | 7,395                           | 14,047  | 529  | 673                                 | 82                   | 0                      | 22,726   | 22,297,457                             |
| 12   | 3,974                           | 9,049   | 181  | 138                                 | 20                   | 0                      | 13,362   | 13,499,726                             |
| 13   | 7,698                           | 6,281   | 158  | 628                                 | 34                   | 0                      | 14,799   | 10,908,547                             |
| 14   | 10,245                          | 22,770  | 638  | 132                                 | 55                   | 93                     | 33,933   | 24,326,974                             |
| 15   | 1,874                           | 12,397  | 662  | 2,281                               | 62                   | 0                      | 17,276   | 19,293,251                             |
| 16   | 905                             | 7,823   | 875  | 411                                 | 47                   | 0                      | 10,061   | 13,516,833                             |
| 17   | 3,126                           | 10,056  | 6,214  | 155                                 | 220                  | 0                      | 19,771   | 15,356,754                             |
| 18   | 4,753                           | 21,852  | 3,727  | 104                                 | 111                  | 0                      | 30,547   | 23,015,544                             |
| TOTAL  | 137,323                         | 208,504 | 17,552   | 5,347                               | 2,630                | 384                    | 371,740  | 308,449,807                            |
| % of Total                                       | 36.9%                           | 56.1%   | 4.7%   | 1.4%                                | 0.7%                 | 0.1%                   | 100%   | <u> </u>                               |
| Estimated % of<br>U.S. Population*,<br>July 2008 | 12.9%                           | 79.8%   | 4.6%   | 1.0%                                | 1.7%                 | 0.0%                   | 100.0%   |  |

\*Based on data for the 50 U.S. states and Washington, DC.

NOTE: Data are compiled by the Networks using Form CMS-2728, which is typically completed by facilities. The form also provides data on ethnicity, defined as "Hispanic or Latino" or "not Hispanic or Latino" (data not shown). Race data are reported here to highlight disproportionate burdens of disease for certain population groups, especially at the national level.

SOURCES: Patient data: Networks 1–18 2008 Summary Annual Report Data Overview Forms. Population data for 50 U.S. states and Puerto Rico: U.S. Census Bureau Population Estimates for July 2008, retrieved from: http://factfinder.census.gov. Population data for American Samoa, Guam, and the Northern Mariana Islands: Network 17 Annual Report 2008. Population Data for Virgin Islands: Network 3 Annual Report 2007.

TABLE 11

Prevalent Dialysis Patients by Primary Diagnosis as of December 31, 2008

| Network    | Diabetes | Hypertension | Glomerulonephritis | Cystic Kidney<br>Disease | Other* | Unknown | Missing | Total Number of<br>Dialysis Patients as of<br>December 31, 2008 |
|------------|----------|--------------|--------------------|--------------------------|--------|---------|---------|---|
| 1          | 4,727    | 2,627        | 1,548              | 463                      | 2,046  | 555     | 0       | 11,966  |
| 2          | 9,784    | 6,007        | 2,632              | 706                      | 3,301  | 1,603   | 181     | 24,214  |
| 3          | 7,159    | 3,903        | 1,646              | 415                      | 1,975  | 300     | 6       | 15,404  |
| 4          | 6,758    | 4,304        | 1,661              | 483                      | 2,369  | 651     | 0       | 16,226  |
| 5          | 8,559    | 7,319        | 1,978              | 491                      | 2,447  | 684     | 51      | 21,529  |
| 6          | 14,618   | 11,795       | 3,428              | 800                      | 3,826  | 1,183   | 0       | 35,650  |
| 7          | 8,513    | 6,777        | 1,994              | 657                      | 2,739  | 60      | 532     | 21,272  |
| 8          | 8,516    | 7,426        | 1,842              | 537                      | 2,201  | 555     | 0       | 21,077  |
| 9          | 11,090   | 6,667        | 2,611              | 690                      | 3,230  | 1,968   | 12      | 26,268  |
| 10         | 6,092    | 5,121        | 1,347              | 347                      | 1,691  | 1,021   | 40      | 15,659  |
| 11         | 9,482    | 6,220        | 2,459              | 682                      | 3,105  | 778     | 0       | 22,726  |
| 12         | 5,602    | 3,762        | 1,430              | 403                      | 1,710  | 453     | 2       | 13,362  |
| 13         | 6,212    | 5,014        | 1,202              | 392                      | 1,616  | 363     | 0       | 14,799  |
| 14         | 17,920   | 8,458        | 2,595              | 715                      | 3,248  | 901     | 96      | 33,933  |
| 15         | 9,070    | 3,217        | 1,839              | 481                      | 2,096  | 573     | 0       | 17,276  |
| 16         | 4,221    | 1,940        | 1,366              | 406                      | 1,632  | 496     | 0       | 10,061  |
| 17         | 9,688    | 4,597        | 2,275              | 524                      | 2,011  | 676     | 0       | 19,771  |
| 18         | 14,197   | 8,470        | 2,695              | 702                      | 2,846  | 1,637   | 0       | 30,547  |
| TOTAL      | 162,208  | 103,624      | 36,548             | 9,894                    | 44,089 | 14,457  | 920     | 371,740   |
| % of Total | 43.6%    | 27.9%        | 9.8%               | 2.7%                     | 11.9%  | 3.9%    | 0.2%    | 100%  |

\*Includes "Other" and "Other Urologic."

NOTE: Reporting based on data recorded on Form CMS-2728.

TABLE 12

Number of In-Center Hemodialysis Patients as of December 31, 2007, and December 31, 2008

| Network | Number of In-Center Dialysis Patients* as of December 31, 2007 | Number of In-Center Dialysis Patients*<br>as of December 31, 2008 | % Change |
|---------|--|---|----------|
| 1       | 10,303   | 10,699  | 4%       |
| 2       | 22,277   | 22,821  | 2%       |
| 3       | 13,952   | 14,459  | 4%       |
| 4       | 14,689   | 14,945  | 2%       |
| 5       | 19,199   | 19,729  | 3%       |
| 6       | 31,202   | 32,401  | 4%       |
| 7       | 18,611   | 19,492  | 5%       |
| 8       | 18,330   | 19,134  | 4%       |
| 9       | 23,106   | 23,901  | 3%       |
| 10      | 13,539   | 13,758  | 2%       |
| 11      | 20,320   | 20,819  | 2%       |
| 12      | 11,586   | 11,796  | 2%       |
| 13      | 12,933   | 13,548  | 5%       |
| 14      | 29,869   | 31,382  | 5%       |
| 15      | 15,117   | 15,822  | 5%       |
| 16      | 8,332  | 8,700   | 4%       |
| 17      | 16,767   | 17,605  | 5%       |
| 18      | 26,674   | 27,950  | 5%       |
| TOTAL   | 326,806  | 338,961   | 4%       |

<sup>\*</sup>Includes patients in training for home modalities.

NOTE: Data limited to information from facilities submitting a Facility Survey Form (CMS-2744) and information contained in Network SIMS databases.

TABLE 13

Number of Home Dialysis Patients by Modality as of December 31, 2007, and December 31, 2008

|         | Hemodialysis |       | is          | Continuous Ambulatory<br>Peritoneal Dialysis |        |             | Continuous Cycling Peritoneal<br>Dialysis |        |             |      | eritoneal<br>ysis* | То     | Total  |  |
|---------|--------------|-------|-------------|--|--------|-------------|---|--------|-------------|------|--------------------|--------|--------|--|
| Network | 2007         | 2008  | %<br>Change | 2007   | 2008   | %<br>Change | 2007                                      | 2008   | %<br>Change | 2007 | 2008               | 2007   | 2008   |  |
| 1       | 104          | 122   | 17%         | 396  | 400    | 1%          | 755                                       | 742    | -2%         | 0    | 2                  | 1,255  | 1,266  |  |
| 2       | 157          | 167   | 6%          | 450  | 480    | 7%          | 747                                       | 770    | 3%          | 1    | 0                  | 1,355  | 1,417  |  |
| 3       | 44           | 59    | 34%         | 183  | 186    | 2%          | 674                                       | 636    | -6%         | 0    | 0                  | 901    | 881    |  |
| 4       | 116          | 175   | 51%         | 299  | 306    | 2%          | 663                                       | 668    | 1%          | 2    | 5                  | 1,080  | 1,154  |  |
| 5       | 174          | 216   | 24%         | 607  | 596    | -2%         | 1,004                                     | 959    | -4%         | 1    | 2                  | 1,786  | 1,773  |  |
| 6       | 281          | 371   | 32%         | 948  | 1,011  | 7%          | 1,858                                     | 1,840  | -1%         | 3    | 5                  | 3,090  | 3,227  |  |
| 7       | 179          | 194   | 8%          | 481  | 474    | -1%         | 1,038                                     | 1,033  | 0%          | 0    | 0                  | 1,698  | 1,701  |  |
| 8       | 145          | 169   | 17%         | 657  | 650    | -1%         | 1,134                                     | 1,131  | 0%          | 0    | 7                  | 1,936  | 1,957  |  |
| 9       | 296          | 298   | 1%          | 994  | 964    | -3%         | 1,133                                     | 1,158  | 2%          | 1    | 2                  | 2,424  | 2,422  |  |
| 10      | 452          | 618   | 37%         | 433  | 409    | -6%         | 733                                       | 769    | 5%          | 1    | 2                  | 1,619  | 1,798  |  |
| 11      | 265          | 325   | 23%         | 865  | 793    | -8%         | 775                                       | 795    | 3%          | 0    | 0                  | 1,905  | 1,913  |  |
| 12      | 199          | 257   | 29%         | 514  | 514    | 0%          | 758                                       | 807    | 6%          | 1    | 1                  | 1,472  | 1,579  |  |
| 13      | 63           | 107   | 70%         | 358  | 336    | -6%         | 772                                       | 807    | 5%          | 0    | 1                  | 1,193  | 1,251  |  |
| 14      | 280          | 320   | 14%         | 676  | 707    | 5%          | 1,545                                     | 1,549  | 0%          | 0    | 1                  | 2,501  | 2,577  |  |
| 15      | 114          | 135   | 18%         | 431  | 465    | 8%          | 857                                       | 831    | -3%         | 0    | 0                  | 1,402  | 1,431  |  |
| 16      | 203          | 227   | 12%         | 354  | 358    | 1%          | 750                                       | 771    | 3%          | 4    | 5                  | 1,311  | 1,361  |  |
| 17      | 142          | 198   | 39%         | 595  | 640    | 8%          | 1,282                                     | 1,253  | -2%         | 1    | 1                  | 2,020  | 2,092  |  |
| 18      | 157          | 187   | 19%         | 883  | 843    | -5%         | 1,437                                     | 1,574  | 10%         | 2    | 2                  | 2,479  | 2,606  |  |
| TOTAL   | 3,371        | 4,145 | 23%         | 10,124                                       | 10,132 | 0%          | 17,915                                    | 18,093 | 1%          | 17   | 36                 | 31,427 | 32,406 |  |

<sup>\*</sup>Incudes Intermittent Peritoneal Dialysis which is similar to Continuous Cycling Peritoneal Dialysis but is usually performed in a hospital.

TABLE 14

Number of Patients Using In-Center and Home Dialysis as of December 31, 2007, and December 31, 2008

|         | In      | -Center Dialy | sis         | ]      | Home Dialysis | 8           |         | Total   |             |  |  |
|---------|---------|---------------|-------------|--------|---------------|-------------|---------|---------|-------------|--|--|
| Network | 2007    | 2008          | %<br>Change | 2007   | 2008          | %<br>Change | 2007    | 2008    | %<br>Change |  |  |
| 1       | 10,303  | 10,699        | 4%          | 1,255  | 1,266         | 1%          | 11,558  | 11,965  | 4%          |  |  |
| 2       | 22,277  | 22,821        | 2%          | 1,355  | 1,417         | 5%          | 23,632  | 24,238  | 3%          |  |  |
| 3       | 13,952  | 14,459        | 4%          | 901    | 881           | -2%         | 14,853  | 15,340  | 3%          |  |  |
| 4       | 14,689  | 14,945        | 2%          | 1,080  | 1,154         | 7%          | 15,769  | 16,099  | 2%          |  |  |
| 5       | 19,199  | 19,729        | 3%          | 1,786  | 1,773         | -1%         | 20,985  | 21,502  | 2%          |  |  |
| 6       | 31,202  | 32,401        | 4%          | 3,090  | 3,227         | 4%          | 34,292  | 35,628  | 4%          |  |  |
| 7       | 18,611  | 19,492        | 5%          | 1,698  | 1,701         | 0%          | 20,309  | 21,193  | 4%          |  |  |
| 8       | 18,330  | 19,134        | 4%          | 1,936  | 1,957         | 1%          | 20,266  | 21,091  | 4%          |  |  |
| 9       | 23,106  | 23,901        | 3%          | 2,424  | 2,422         | 0%          | 25,530  | 26,323  | 3%          |  |  |
| 10      | 13,539  | 13,758        | 2%          | 1,619  | 1,798         | 11%         | 15,158  | 15,556  | 3%          |  |  |
| 11      | 20,320  | 20,819        | 2%          | 1,905  | 1,913         | 0%          | 22,225  | 22,732  | 2%          |  |  |
| 12      | 11,586  | 11,796        | 2%          | 1,472  | 1,579         | 7%          | 13,058  | 13,375  | 2%          |  |  |
| 13      | 12,933  | 13,548        | 5%          | 1,193  | 1,251         | 5%          | 14,126  | 14,799  | 5%          |  |  |
| 14      | 29,869  | 31,382        | 5%          | 2,501  | 2,577         | 3%          | 32,370  | 33,959  | 5%          |  |  |
| 15      | 15,117  | 15,822        | 5%          | 1,402  | 1,431         | 2%          | 16,519  | 17,253  | 4%          |  |  |
| 16      | 8,332   | 8,700         | 4%          | 1,311  | 1,361         | 4%          | 9,643   | 10,061  | 4%          |  |  |
| 17      | 16,767  | 17,605        | 5%          | 2,020  | 2,092         | 4%          | 18,787  | 19,697  | 5%          |  |  |
| 18      | 26,674  | 27,950        | 5%          | 2,479  | 2,606         | 5%          | 29,153  | 30,556  | 5%          |  |  |
| TOTAL   | 326,806 | 338,961       | 4%          | 31,427 | 32,406        | 3%          | 358,233 | 371,367 | 4%          |  |  |

NOTE: Due to differences in data abstraction protocols and the dynamic nature of the patient population, the total prevalence reported in this table (n = 371,367) differs from the total prevalence reported in Tables 1, 8, 9, 10, and 11 (n = 371,740)

TABLE 15

Renal Transplant Recipients by Age Group (in Years), Calendar Year 2008

| Network    | 0–19 | 20–29 | 30–39 | 40–49 | 50–59 | 60–69 | 70–79 | ≥ 80 | Total Number of<br>Transplant Recipients,<br>Calendar Year 2008 |
|------------|------|-------|-------|-------|-------|-------|-------|------|---|
| 1          | 45   | 47    | 90    | 157   | 173   | 164   | 45    | 1    | 722   |
| 2          | 54   | 86    | 160   | 256   | 318   | 300   | 121   | 7    | 1,302   |
| 3          | 25   | 42    | 69    | 110   | 156   | 119   | 27    | 1    | 549   |
| 4          | 64   | 52    | 84    | 155   | 277   | 213   | 102   | 9    | 956   |
| 5          | 46   | 78    | 158   | 213   | 307   | 235   | 69    | 3    | 1,099   |
| 6          | 73   | 82    | 189   | 220   | 273   | 253   | 54    | 2    | 1,146   |
| 7          | 36   | 57    | 124   | 209   | 250   | 242   | 85    | 3    | 1,006   |
| 8          | 40   | 46    | 106   | 161   | 191   | 170   | 27    | 1    | 742   |
| 9          | 33   | 67    | 126   | 234   | 318   | 264   | 68    | 2    | 1,112   |
| 10         | 36   | 59    | 110   | 145   | 206   | 148   | 43    | 0    | 747   |
| 11         | 77   | 112   | 193   | 349   | 428   | 386   | 97    | 4    | 1,646   |
| 12         | 48   | 68    | 93    | 129   | 223   | 170   | 41    | 1    | 773   |
| 13         | 25   | 39    | 77    | 112   | 120   | 100   | 29    | 2    | 504   |
| 14         | 70   | 115   | 216   | 302   | 328   | 232   | 41    | 0    | 1,304   |
| 15         | 41   | 79    | 116   | 187   | 236   | 186   | 64    | 1    | 910   |
| 16         | 34   | 35    | 74    | 115   | 137   | 111   | 39    | 0    | 545   |
| 17         | 57   | 56    | 113   | 158   | 219   | 208   | 53    | 2    | 866   |
| 18         | 83   | 108   | 173   | 262   | 300   | 217   | 52    | 0    | 1,195   |
| TOTAL      | 887  | 1,228 | 2,271 | 3,474 | 4,460 | 3,718 | 1,057 | 39   | 17,124  |
| % of Total | 5.2% | 7.2%  | 13.3% | 20.3% | 26.0% | 21.7% | 6.2%  | 0.2% | 100%  |

NOTE: Reporting based on data recorded on Form CMS-2728.

TABLE 16

Renal Transplant Recipients by Gender, Calendar Year 2008

| Network    | Male   | Female | Unknown | Total Number of<br>Transplant Recipients,<br>Calendar Year 2008 |
|------------|--------|--------|---------|---|
| 1          | 440    | 282    | 0       | 722   |
| 2          | 798    | 504    | 0       | 1,302   |
| 3          | 345    | 204    | 0       | 549   |
| 4          | 616    | 340    | 0       | 956   |
| 5          | 643    | 456    | 0       | 1,099   |
| 6          | 678    | 468    | 0       | 1,146   |
| 7          | 635    | 371    | 0       | 1,006   |
| 8          | 462    | 280    | 0       | 742   |
| 9          | 697    | 415    | 0       | 1,112   |
| 10         | 476    | 271    | 0       | 747   |
| 11         | 1,008  | 638    | 0       | 1,646   |
| 12         | 475    | 298    | 0       | 773   |
| 13         | 315    | 189    | 0       | 504   |
| 14         | 775    | 527    | 2       | 1,304   |
| 15         | 532    | 378    | 0       | 910   |
| 16         | 325    | 220    | 0       | 545   |
| 17         | 490    | 376    | 0       | 866   |
| 18         | 723    | 472    | 0       | 1,195   |
| TOTAL      | 10,433 | 6,689  | 2       | 17,124  |
| % of Total | 60.9%  | 39.1%  | 0.0%    | 100%  |

NOTE: Reporting based on data recorded on Form CMS-2728.

TABLE 17

Renal Transplant Recipients by Reported Race, Calender Year 2008

| Network    | Black or African<br>American | White  | Asian and Native<br>Hawaiian or Other<br>Pacific Islander | American Indian or<br>Alaska Native | Two or More<br>Races | Missing and<br>Unknown | Total Number of<br>Transplant Recipients,<br>Calendar Year 2008 |
|------------|------------------------------|--------|---|-------------------------------------|----------------------|------------------------|---|
| 1          | 105                          | 586    | 23  | 2                                   | 6                    | 0                      | 722   |
| 2          | 378                          | 789    | 90  | 6                                   | 14                   | 25                     | 1,302   |
| 3          | 168                          | 314    | 25  | 0                                   | 40                   | 2                      | 549   |
| 4          | 236                          | 675    | 39  | 2                                   | 4                    | 0                      | 956   |
| 5          | 478                          | 568    | 39  | 2                                   | 2                    | 10                     | 1,099   |
| 6          | 514                          | 592    | 23  | 14                                  | 1                    | 2                      | 1,146   |
| 7          | 304                          | 651    | 39  | 6                                   | 6                    | 0                      | 1,006   |
| 8          | 308                          | 422    | 10  | 1                                   | 1                    | 0                      | 742   |
| 9          | 230                          | 858    | 16  | 0                                   | 4                    | 4                      | 1,112   |
| 10         | 216                          | 468    | 31  | 0                                   | 7                    | 25                     | 747   |
| 11         | 266                          | 1,268  | 62  | 44                                  | 6                    | 0                      | 1,646   |
| 12         | 138                          | 599    | 23  | 8                                   | 5                    | 0                      | 773   |
| 13         | 197                          | 283    | 11  | 13                                  | 0                    | 0                      | 504   |
| 14         | 278                          | 919    | 43  | 5                                   | 13                   | 46                     | 1,304   |
| 15         | 57                           | 749    | 40  | 63                                  | 1                    | 0                      | 910   |
| 16         | 43                           | 431    | 59  | 9                                   | 3                    | 0                      | 545   |
| 17         | 92                           | 548    | 210   | 9                                   | 7                    | 0                      | 866   |
| 18         | 140                          | 907    | 135   | 3                                   | 10                   | 0                      | 1,195   |
| TOTAL      | 4,148                        | 11,627 | 918   | 187                                 | 130                  | 114                    | 17,124  |
| % of Total | 24.2%                        | 67.9%  | 5.4%  | 1.1%                                | 0.8%                 | 0.7%                   | 100%  |

<sup>\*</sup> Reporting based on data recorded on Form CMS-2728.

Data are compiled by the Networks using Form CMS-2728, which is typically completed by facilities. The form also provides data on ethnicity, defined as "Hispanic or Latino" or "not Hispanic or Latino" (data not shown). Race data are reported here to highlight disproportionate burdens of disease for certain population groups.

TABLE 18

Renal Transplant Recipients by Donor Type, Calendar Year 2008

| Network | Deceased Donors | Living Related<br>Donors | Living Unrelated<br>Donors | Total Number of Renal<br>Transplant Recipients, Calendar<br>Year 2008 |
|---------|-----------------|--------------------------|----------------------------|---|
| 1       | 392             | 196                      | 134                        | 722   |
| 2       | 752             | 351                      | 199                        | 1,302   |
| 3       | 373             | 103                      | 73                         | 549   |
| 4       | 692             | 207                      | 57                         | 956   |
| 5       | 691             | 252                      | 156                        | 1,099   |
| 6       | 874             | 184                      | 88                         | 1,146   |
| 7       | 805             | 140                      | 61                         | 1,006   |
| 8       | 538             | 123                      | 81                         | 742   |
| 9       | 705             | 311                      | 96                         | 1,112   |
| 10      | 423             | 260                      | 64                         | 747   |
| 11      | 946             | 388                      | 312                        | 1,646   |
| 12      | 554             | 151                      | 68                         | 773   |
| 13      | 397             | 78                       | 29                         | 504   |
| 14      | 905             | 251                      | 148                        | 1,304   |
| 15      | 524             | 221                      | 165                        | 910   |
| 16      | 337             | 103                      | 105                        | 545   |
| 17      | 552             | 172                      | 143                        | 867 *   |
| 18      | 790             | 245                      | 160                        | 1,195   |
| TOTAL   | 11,250          | 3,736                    | 2,139                      | 17,125  |

<sup>\*</sup>One transplant recipient received two kidney transplants in 2008; therefore, the total number of transplants (n = 867) for Network 17 differs from the total number of transplant recipients (n = 866) as indicated in Tables 15, 16, and 17.

SOURCE: United Network for Organ Sharing data as reported in Networks 1–18 2008 Summary Annual Report Data Overview Forms.

TABLE 19

Percent of In-Center and Home Dialysis Patients with an Arteriovenous Fistula (AVF), by
Network, December 2008, Compared with Network Baseline and Goal

| Network | Network Baseline:<br>3rd Quarter 2008 | Network Goal: 2008 | Patients with an AVF as of<br>December 31, 2008 |
|---------|---------------------------------------|--------------------|---|
| 1       | 53.3                                  | 54.6               | 55.9  |
| 2       | 51.2                                  | 53.1               | 55.5  |
| 3       | 44.8                                  | 48.8               | 51.4  |
| 4       | 46.7                                  | 48.4               | 50.3  |
| 5       | 41.4                                  | 45.4               | 48.2  |
| 6       | 43.7                                  | 45.8               | 47.1  |
| 7       | 45.7                                  | 49.7               | 51.6  |
| 8       | 41.5                                  | 45.5               | 48.6  |
| 9       | 44.2                                  | 48.8               | 47.3  |
| 10      | 45.8                                  | 50.3               | 49.1  |
| 11      | 43.0                                  | 47.0               | 49.8  |
| 12      | 48.9                                  | 52.3               | 50.7  |
| 13      | 43.1                                  | 47.0               | 49.9  |
| 14      | 44.9                                  | 52.0               | 50.8  |
| 15      | 53.3                                  | 57.4               | 57.3  |
| 16      | 60.6                                  | 61.7               | 63.8  |
| 17      | 53.2                                  | 56.8               | 56.9  |
| 18      | 50.2                                  | 53.4               | 54.9  |
| Mean    | 47.5                                  | 51.0               | 52.2  |

TABLE 20

Vocational Rehabilitation of Prevalent Dialysis Patients Aged 18–54 Years, Number of Dialysis Facilities, and Facilities Offering Dialysis after Regular Business Hours, as of December 31, 2008

Percent Employed Number of Percent of **Number Employed Number of Dialysis** Number Percent through **Facilities Facilities** Number of **Patients Aged** Number Percent through Vocational Vocational Attending Attending Dialysis Offering Network Offering 18-54 Years as of Rehablitation Employed\* Employed\* Dialysis after Dialysis after Rehablitation School\* School\* **Facilities** December 31, 2008 Services\* Services\* 5:00 PM 5:00 PM 1 3,100 768 25% 112 4% 69 2% 166 59 36% 2 2% 113 7,093 1,338 19% 150 2% 169 237 48% 3 4,385 1,241 28% 126 3% 127 3% 166 52 31% 4 4,543 900 20% 54 1% 69 2% 265 65 25% 5 7,057 1,673 24% 223 3% 167 2% 312 72 23% 6 13,031 1,935 15% 255 2% 324 2% 547 21 4% 7 42 6,656 1.350 20% 285 4% 195 3% 350 12% 8 7,591 961 13% 86 1% 61 1% 339 16 5% 9 7,800 714 9% 77 1% 79 1% 472 77 16% 25 42 10 4,688 520 11% 1% 56 1% 218 19% 11 6,526 1,317 20% 115 2% 194 3% 402 95 24% 12 3,978 896 23% 51 1% 6 0% 266 27 10% 13 5,356 873 16% 122 2% 115 2% 277 26 9% 14 11,892 2,374 20% 206 2% 306 3% 453 52 11% 15 5,263 1,473 28% 175 3% 180 3% 273 67 25% 894 29% 73 50% 16 3,116 68 2% 96 3% 147 17 4% 57 6,191 1,384 22% 191 3% 219 204 28% 18 9,970 2,637 26% 289 3% 433 4% 314 92 29% **TOTAL** 118,236 23,248 20% 2% 2,865 2% 5,408 1,048 19% 2,610

\*Full- or part-time.

SOURCES: Facilities offering dialysis after 5 PM: Computer Sciences Corporation. All other data: Networks 1-18 2008 Summary Annual Report Data Overview Forms.

TABLE 21

Patient Complaints and Grievances, Calendar Year 2008

| Network | Number of Prevalent<br>Dialysis Patients as of<br>December 31, 2008 | Number of<br>Complaints | Number of<br>Grievances | Rate of Complaints per<br>1,000 Prevalent<br>Patients |
|---------|---|-------------------------|-------------------------|---|
| 1       | 11,966  | 7                       | 0                       | 0.58  |
| 2       | 24,214  | 81                      | 0                       | 3.35  |
| 3       | 15,404  | 45                      | 0                       | 2.92  |
| 4       | 16,226  | 46                      | 1                       | 2.83  |
| 5       | 21,529  | 57                      | 11                      | 2.65  |
| 6       | 35,650  | 371                     | 8                       | 10.41   |
| 7       | 21,272  | 135                     | 1                       | 6.35  |
| 8       | 21,077  | 47                      | 1                       | 2.23  |
| 9       | 26,268  | 114                     | 2                       | 3.01  |
| 10      | 15,659  | 111                     |                         | 5.01  |
| 11      | 22,726  | 602                     | 0                       | 26.49   |
| 12      | 13,362  | 36                      | 3                       | 2.69  |
| 13      | 14,799  | 43                      | 2                       | 2.91  |
| 14      | 33,933  | 79                      | 8                       | 2.33  |
| 15      | 17,276  | 84                      | 0                       | 4.86  |
| 16      | 10,061  | 36                      | 2                       | 3.58  |
| 17      | 19,771  | 41                      | 0                       | 2.07  |
| 18      | 30,547  | 44                      | 12                      | 1.44  |
| TOTAL   | 371,740   | 1,868                   | 51                      |   |
| Mean    |   |                         |                         | 5.03  |

TABLE 22

Incident ESRD Patients, Prevalent Dialysis Patients, and Transplant Recipients by Reported Race, 2008

| Patient Category                                    | Black or African<br>American |       | White   |       | Asian and Native<br>Hawaiian or Other<br>Pacific Islander |      | American<br>Indian or Alaska<br>Native |      | Two or More<br>Races |      | Missing and<br>Unknown |      | Total   |      |
|---|------------------------------|-------|---------|-------|---|------|--|------|----------------------|------|------------------------|------|---------|------|
|   | n                            | %     | n       | %     | n   | %    | n                                      | %    | n                    | %    | n                      | %    | n       | %    |
| Incident ESRD<br>Patients, Calendar<br>Year 2008    | 31,142                       | 27.9% | 73,756  | 66.0% | 4,667   | 4.2% | 1,187                                  | 1.1% | 578                  | 0.5% | 459                    | 0.4% | 111,789 | 100% |
| Prevalent Dialysis Patients as of December 31, 2008 | 137,323                      | 36.9% | 208,504 | 56.1% | 17,552  | 4.7% | 5,347                                  | 1.4% | 2,630                | 0.7% | 384                    | 0.1% | 371,740 | 100% |
| Transplant<br>Recipients, Calendar<br>Year 2008     | 4,148                        | 24.2% | 11,627  | 67.9% | 918   | 5.4% | 187                                    | 1.1% | 130                  | 0.8% | 114                    | 0.7% | 17,124  | 100% |

NOTE: Data are compiled by the Networks using Form CMS-2728, which is typically completed by facilities. The form also provides data on ethnicity, defined as "Hispanic or Latino" or "not Hispanic or Latino" (data not shown). Race data are reported here to highlight disproportionate burdens of disease for certain population groups.

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