

**End Stage Renal Disease (ESRD)  
Network Program  
Annual Report Summary  
1999**



**Prepared by the Forum Clearinghouse of ESRD Networks  
Under Contract to HCFA 500-00-NW15**

ESRD Networks are required by contract with the Health Care Financing Administration (HCFA) to submit an Annual Report covering their activities during each calendar year. This report summarizes those Annual Reports and is submitted to HCFA as a contract deliverable by the Forum Clearinghouse of ESRD Networks. This document covers the time period of January 1, 1999 through December 31, 1999.

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# Annual Report Summary

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## INTRODUCTION

The national End Stage Renal Disease (ESRD) program which extends Medicare benefits to cover the high cost of medical care for most individuals suffering from ESRD was created in October 1972 through the passage of Section 299I of Public Law 92-603. Modifications to the ESRD program were enacted by Congress four years later in order to improve cost effectiveness, ensure the quality of care provided under the program, encourage kidney transplantation and home dialysis, and increase program accountability. This legislation, PL 95-292, authorized the establishment of ESRD Network areas and Network organizations, consistent with criteria determined by the Secretary of the Department of Health and Human Services. The legislation mandated 32 geographic areas and organizations, but in 1987 Congress reduced the number to the existing 18 Networks (see front cover). This report summarizes the annual reports submitted by these 18 Network organizations for calendar year 1999.

## ESRD POPULATION & CHARACTERISTICS

Although the ESRD population is less than 1% of the entire U.S. population it continues to increase at a rate of 5% per year impacting all races, age groups and socioeconomic standings. Because the ESRD Network organizations cover all 50 states plus Puerto Rico, Commonwealth of the Northern Mariana Islands, Guam, and the U.S. Virgin Islands, much variation is seen in both the overall population and the ESRD population. While California (Networks 17 & 18) has the largest state population, the state of Georgia has the largest population on dialysis. At the end of 1999 there were 262,062 patients being dialyzed and 90,525 new ESRD patients, (Appendix A).

**Table 1**  
**ESRD INCIDENCE RATES BY NETWORK**  
**Calendar Year 1999**

<b>Network based Patients' Residence</b>	<b>Initiated ESRD Therapy</b>	<b>General Population</b>	<b>Incidence Rate Per Million Population</b>
<b>1</b>	3,453	13,495,933	255.85
<b>2</b>	6,291	18,196,601	345.72
<b>3</b>	4,350	12,153,027	357.94
<b>4</b>	4,976	12,747,554	390.35
<b>5</b>	5,576	14,370,474	388.02
<b>6</b>	6,779	19,324,765	350.79
<b>7</b>	5,490	15,111,244	363.31
<b>8</b>	4,742	12,622,016	375.69
<b>9/10</b>	11,243	33,288,750	337.74
<b>11</b>	5,935	21,256,528	279.21
<b>12</b>	3,782	12,657,831	298.79
<b>13</b>	3,908	10,281,452	380.10
<b>14</b>	6,647	20,044,141	331.62
<b>15</b>	3,933	14,993,000	262.32

<b>Network based Patients' Residence</b>	<b>Initiated ESRD Therapy</b>	<b>General Population</b>	<b>Incidence Rate Per Million Population</b>
<b>16</b>	2,491	11,826,494	210.63
<b>17/18*</b>	10,929	34,615,583	315.72
<b>Total</b>	<b>90,525</b>	<b>276,985,393</b>	<b>326.82</b>

Source: Networks 1-18 Annual Reports, 1999

\*Networks 17 and 18 have been combined to incorporate the state of California. Hawaii and American territories are included.

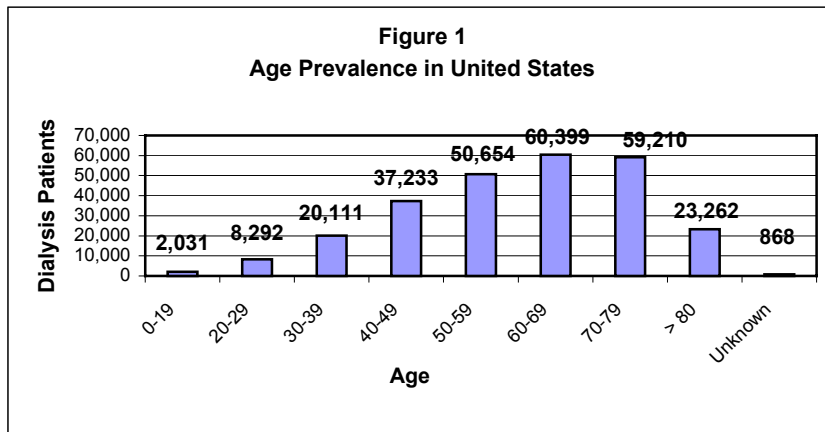
## AGE

In 1999 a majority of the ESRD patients were between the ages of 60 and 79 and the pediatric population remained relatively small with less than one percent of the ESRD population under 20 years old (Table 2 and Figure 1). This same age distribution can be seen in the incident population (Appendix B). These distributions have remained the same over the past three years.

**Table 2**  
**PREVALENCE OF DIALYSIS POPULATION**  
**BY AGE AND NETWORK WHERE TREATED**  
**December 31, 1999**

<b>Network</b>	<b>0-19</b>	<b>20-29</b>	<b>30-39</b>	<b>40-49</b>	<b>50-59</b>	<b>60-69</b>	<b>70-79</b>	<b>≥80</b>	<b>Unk</b>	<b>Total</b>
<b>1</b>	54	242	681	1,122	1,577	2,164	2,735	1,281	0	9,856
<b>2</b>	148	588	1,534	2,836	3,920	4,538	4,358	1,877	0	19,799
<b>3</b>	83	324	888	1,613	2,430	2,899	2,665	1,054	2	11,958
<b>4</b>	95	315	867	1,589	2,226	2,989	3,434	1,335	0	12,850
<b>5</b>	142	315	1,358	2,519	3,295	3,805	3,657	1,286	402	16,779
<b>6</b>	133	822	2,009	3,722	5,093	5,596	4,565	1,546	7	23,493
<b>7</b>	107	412	686	1,969	2,715	3,367	3,651	1,652	401	14,960
<b>8</b>	114	562	1,261	2,380	3,131	3,631	3,099	1,034	0	15,212
<b>9</b>	154	551	1,397	2,471	3,272	4,151	4,281	1,615	39	17,931
<b>10</b>	98	352	808	1,608	2,133	2,547	2,685	1,190	15	11,436
<b>11</b>	105	517	1,200	2,135	2,862	3,298	4,131	1,876	0	16,124
<b>12</b>	93	324	764	1,449	1,732	2,276	2,472	1,057	0	10,167
<b>13</b>	80	444	966	1,811	2,321	2,728	2,222	785	0	11,357
<b>14</b>	179	731	1,773	3,191	4,452	5,047	4,149	1,301	2	20,825
<b>15</b>	99	380	839	1,473	2,166	2,598	2,467	821	0	10,843
<b>16</b>	66	265	558	947	1,223	1,427	1,490	598		6,574
<b>17</b>	66	394	932	1,790	2,502	2,906	2,894	1,289	2	12,775
<b>18</b>	215	754	1,590	2,608	3,604	4,432	4,255	1,665	0	19,123
<b>Total</b>	<b>2,031</b>	<b>8,292</b>	<b>20,111</b>	<b>37,233</b>	<b>50,654</b>	<b>60,399</b>	<b>59,210</b>	<b>23,262</b>	<b>868</b>	<b>262,062</b>
<b>% Total</b>	<b>1%</b>	<b>3%</b>	<b>8%</b>	<b>14%</b>	<b>19%</b>	<b>23%</b>	<b>23%</b>	<b>9%</b>	<b>0%</b>	<b>100%</b>

Source: Networks 1-18 Annual Reports, 1999



Source: Networks 1-18 Annual Reports, 1999

### RACE

While the vast majority of ESRD patients are White, the number of Blacks and Native Americans with ESRD is disproportionately high compared to the U.S. population. While Black Americans comprise 13% of the population they make up 38% of the total ESRD population. Network 6 has a large population of Blacks and Network 15 is home to a large number of Native Americans. Network 1 has a higher population of Whites, 76% compared to the average of 52%. Appendices C and D present tables comparing the dialysis prevalence and ESRD incident populations by race and Network.

### DIAGNOSIS

The leading cause of renal failure in the United States is diabetes. Table 3 and Figure 2 categorize prevalent dialysis patients by primary diagnosis. A list of primary causes for ESRD can be found in Appendix E.

**Table 3**  
**PREVALENCE OF DIALYSIS POPULATION**  
**BY PRIMARY DIAGNOSIS AND NETWORK WHERE TREATED**  
**December 31, 1999**

Network	Diabetes	Hypertension	GN	Cystic Kidney	Other <sup>1</sup>	Unknown <sup>2</sup>	Total
1	3,580	2,379	1,589	496	1,805	7	9,856
2	7,083	4,693	2,847	636	2,791	1,749	19,799
3	4,891	3,012	1,946	505	1,276	328	11,958
4	4,871	3,511	1,783	424	2,260	1	12,850
5	6,057	5,498	2,982	700	1,542	0	16,779
6	8,141	7,135	2,397	687	2,680	2,453	23,493
7	5,322	4,820	1,858	678	2,281	1	14,960
8	5,611	5,332	1,793	605	1,813	58	15,212
9	7,312	4,266	2,748	575	2,989	41	17,931
10	4,045	3,622	1,460	311	1,940	58	11,436
11	6,325	4,359	1,904	510	2,476	550	16,124
12	3,993	2,762	670	525	1,816	401	10,167
13	4,555	3,929	1,424	419	721	309	11,357
14	9,863	5,085	2,572	702	2,544	59	20,825



Network	Diabetes	Hypertension	GN	Cystic Kidney	Other <sup>1</sup>	Unknown <sup>2</sup>	Total
15	5,242	1,827	1,401	493	1,872	8	10,843
16	2,602	1,145	1,222	531	765	309	6,574
17	5,448	2,777	2,429	756	1,365	0	12,775
18	8,103	5,381	2,672	786	2,181	0	19,123
<b>Total</b>	<b>103,044</b>	<b>71,533</b>	<b>35,697</b>	<b>10,339</b>	<b>35,117</b>	<b>6,332</b>	<b>262,062</b>
<b>%</b>	<b>39%</b>	<b>27%</b>	<b>14%</b>	<b>4%</b>	<b>13%</b>	<b>2%</b>	<b>99%</b>

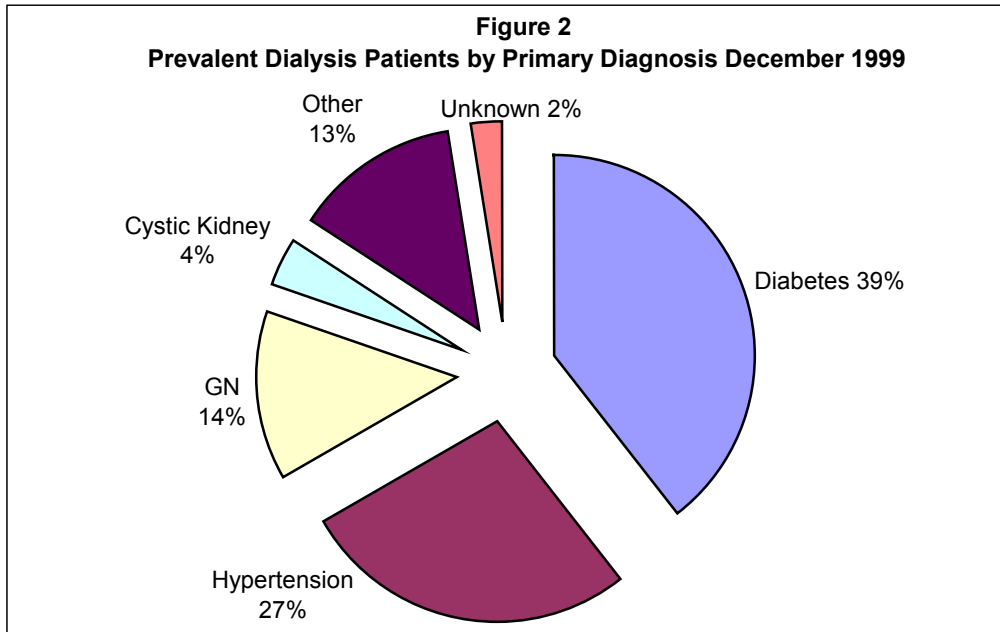
Source: Networks 1-18 Annual Reports, 1999

<sup>1</sup>Other refers to those primary causes listed in Appendix G

<sup>2</sup>Unknown refers to causes both unknown and unreported

As shown by Figure 2, diabetes represented 39% of the prevalent dialysis patient population in 1999. Hypertension followed with 27%, glomerulonephritis with 14% and other causes accounted for 13% of the dialysis population with 2% of patients having an unknown primary cause. The percentage of patients with a primary diagnosis of diabetes remained the same as 1998. Appendix F illustrates the primary diagnosis of incident patients by Network. While diabetes is the most common cause of ESRD it is prominently the cause of ESRD in women while hypertension is most common cause of ESRD in men (USRDS 1999).

Given the diverse patient populations seen within each geographic region it is surprising that there is little variation between the Network populations with respect to the diagnosis of their prevalent populations. All Networks reported diabetes as the primary cause of renal failure in 1999 but Network 14, at 51%, had the highest percentage of patients with this primary diagnosis. Network 8 had a higher percentage of patients with hypertension, 33%.



Source: Networks 1-18 Annual Reports, 1999

## GENDER

In 1999, males represented over half of the ESRD incident and dialysis prevalent population, 53%. With the exception of Network 8, all Networks reported a higher ratio of males to females (Appendix H).

## TREATMENT MODALITY

Today, ESRD patients have a variety of choices for outpatient renal replacement therapy. They have the option of dialyzing at home, in a hospital-based facility, or an independent facility offering treatment. Some transplant centers, in addition to providing kidney transplants, offer dialysis services. Appendices I and J display the number of dialysis patients in each Network by modality.

Table 4 lists Medicare ESRD providers by type of service offered by Network. As expected based on patient populations, Network 6 has the largest number of dialysis providers (314) and Network 16 has the smallest number of providers (96).

While in-center hemodialysis is the predominate modality choice, changes are occurring in peritoneal dialysis (Appendix J). Continuous cycling peritoneal dialysis rose between 1998 and 1999 in most Networks. In-center peritoneal dialysis fell in all Networks as did CAPD (Appendix K).

**Table 4**  
**MEDICARE ESRD PROVIDERS BY TYPE OF SERVICE AND NETWORK**  
**December 31, 1998**

Network	Total	Transplant	Dialysis	Hospital <sup>1</sup>	Independent <sup>1</sup>
1	122	15	118	40	78
2	183	14	181	101	80
3	109	3	108	48	60
4	208	14	189	39	150
5	246	15	240	48	192
6	314	10	308	25	283
7	230	7	226	15	211
8	253	12	246	15	231
9	250	16	244	52	192
10	118	8	116	34	82
11	258	20	249	113	136
12	193	18	182	50	132
13	212	18	203	32	171
14	263	20	247	13	234
15	175	14	166	30	136
16	96	5	93	32	61
17	143	9	136	29	107
18	213	17	203	18	185
<b>Total</b>	<b>3,586</b>	<b>235</b>	<b>3,455</b>	<b>734</b>	<b>2,721</b>

Source: National Listing of Medicare Providers Furnishing Kidney Dialysis and Transplant Services, January 1999 (most current available)

<sup>1</sup> Hospital and Independent counts are included in the total dialysis count.

Note: Detail does not add to total because most transplant centers also provide dialysis services and are counted again as dialysis providers.

According to the annual facility surveys conducted by the Networks, 13,523 transplants were performed at 235 transplant facilities within the United States during 1999. Of these transplants, 8,977 were from cadaveric donors while 3,599 were from living related donors and 814 from living non-related donors. Cadaveric donors represent 66% of transplants performed, but due to decreases in the availability of cadaveric donors, the percent of living and living unrelated donor transplants have increased in recent years and in 1999 represented 33% of all transplants performed. The number of patients waiting for a kidney transplant is listed in Appendix M.

Table 5 and Appendix N list the number of transplants performed by Network. Networks 11 and 14 had 20 transplant centers each. Network 11 performed the largest number of transplants in 1999, 1,422 and had the largest number of transplants by living related donor, 463. Network 3 performed the least number of transplants, 389 and had the least number of transplants by living related donor, 99 and had the fewest number of transplant centers, 3.

**Table 5**  
**RENAL TRANSPLANT RECIPIENTS FOR TRANSPLANT CENTERS BY NETWORK**  
**Calendar Year 1999**

<b>Network</b>	<b>Total Transplants</b>	<b>Cadaveric Donor</b>	<b>Living Related Donor</b>	<b>Living Unrelated Donor</b>	<b>Unknown</b>
<b>1</b>	605	330	200	75	0
<b>2</b>	871	548	256	67	0
<b>3</b>	389	226	99	47	17
<b>4</b>	967	776	157	23	11
<b>5</b>	902	518	273	21	90
<b>6</b>	782	528	212	42	0
<b>7</b>	728	560	132	36	0
<b>8</b>	660	418	211	30	1
<b>9</b>	918	688	226	0	4
<b>10</b>	527	387	137	0	3
<b>11</b>	1,422	801	463	158	0
<b>12</b>	679	438	169	72	0
<b>13</b>	414	288	111	15	0
<b>14</b>	990	735	221	34	0
<b>15</b>	636	382	183	64	7
<b>16</b>	466	273	147	46	0
<b>17</b>	594	407	146	41	0
<b>18</b>	973	674	256	43	0
<b>Total</b>	<b>13,523</b>	<b>8,977</b>	<b>3,599</b>	<b>814</b>	<b>133</b>

Source: Networks 1-18 Annual Reports, 1999

## NETWORK DESCRIPTION

The program began in 1977 when HCFA published the final regulations establishing 32 Network Coordinating Councils to administer the newly funded ESRD program. With only 40,000 dialysis patients receiving care in 600 facilities, the Networks' responsibilities focused on organizational activities, health planning tasks, and medical review activities.

By 1987 the ESRD program encompassed over 100,000 patients and 1,800 facilities administering renal replacement therapy. At this time, Congress consolidated the 32 Networks into 18, redistributing and increasing their geographical areas as well as their program responsibilities. Funding mechanisms changed when Congress mandated that \$ 0.50 from the composite rate payment from each dialysis treatment be allocated to fund the Network program. In 1988, HCFA began contracting with the ESRD Networks to meet their legislative responsibilities. These contracts placed greater emphasis on quality improvement activities and standardizing approaches to quality assessment. Networks still collected and analyzed data for quality improvement, but health-planning functions diminished.

The Networks began working on a new three-year Statement of Work (SOW) in July 1997. The contract established a revised ESRD Network Organization Manual that allowed HCFA to efficiently modify some requirements of the ESRD Network program while enabling Networks to better understand contract responsibilities.

The impact of the new manual is particularly important to the daily operations of the Networks. As specified in the Statement of Work, each Network is responsible for conducting activities in the following areas:

1. Quality Improvement
2. Community Information and Resource
3. Administration
4. Information Management

HCFA contracts require each Network to have an Executive Director, a Director of Quality Improvement, and a Director of Data Management as well as other necessary staff to fulfill the contract obligations. The role of the Executive Director is to coordinate the activities of the Network. The Quality Improvement Director coordinates quality-related requirements and creates and implements quality improvement projects. The Data Manager's role is the accurate recording and transmission of data between the facilities, the Network, and HCFA.

In addition to these staff, Networks employ other individuals to accomplish contract responsibilities. Though these positions vary from Network to Network, additional staff in the areas of quality improvement and data are essential for the coordination of the many Network activities. Table 6 shows the type, number and percent of staff employed by each Network.

**Table 6**  
**NETWORK STAFF BY TYPE, NUMBER AND PERCENT**  
**December 31, 1999**

Network	Administrative		Quality		Data		Patient Services		Total Staff
	#	%	#	%	#	%	#	%	
<b>1</b>	3	38%	2	25%	2	25%	1	13%	<b>8</b>
<b>2</b>	3	30%	2	20%	4	40%	1	10%	<b>10</b>
<b>3</b>	2	20%	2	20%	6	60%	0	0%	<b>10</b>
<b>4</b>	3	38%	2	25%	3	38%	0	0%	<b>8</b>
<b>5</b>	3	27%	4	36%	3	27%	1	9%	<b>11</b>
<b>6</b>	3	27%	3	27%	5	45%	0	0%	<b>11</b>
<b>7</b>	2	22%	2	22%	4	44%	1	11%	<b>9</b>
<b>8</b>	2	25%	2	25%	3	38%	1	13%	<b>8</b>
<b>9/10</b>	5	36%	2	14%	4	29%	3	21%	<b>14</b>
<b>11</b>	2	25%	2	25%	4	50%	0	0%	<b>8</b>
<b>12</b>	3	43%	2	29%	2	29%	0	0%	<b>7</b>
<b>13</b>	2	22%	2	22%	4	44%	1	11%	<b>9</b>
<b>14</b>	3	25%	2	17%	5	42%	2	17%	<b>12</b>
<b>15</b>	3	30%	2	20%	4	40%	1	10%	<b>10</b>
<b>16</b>	1	17%	1	17%	4	67%	0	0%	<b>6</b>
<b>17</b>	3	30%	3	30%	3	30%	1	10%	<b>10</b>
<b>18</b>	3	33%	1	11%	4	44%	1	11%	<b>9</b>

Source: Networks 1-18 Annual Reports, 1999

As seen in Table 6, Networks operate with a relatively small number of employees for the size of the ESRD patient population served. The staffing pattern is similar across the Networks, with respect to the number of staff assigned to functional categories but still reflect regional variations. Over sixty percent of the Networks have patient services staff while the other Networks handle these responsibilities through their quality improvement or administrative personnel. The staff classification areas above are for calculation purposes only and often do not indicate the true nature of staff work duties. Due to the small staff size in the Networks an administrative assistant may be responsible for supporting the quality improvement staff a portion of the time and the data staff the other time.

Network staff are supported by a variety of committees with volunteer members from within the Network area. Each Network is required by contract to specify appropriate roles and functions for these committees and each is required to have the following:

- **Network Council:** A body composed of renal providers in the Network area that is representative of the geography and the types of providers/facilities in the entire Network area as well as at least one patient representative. The Network Council serves as a liaison between the provider membership and the Network.
- **Board of Directors (BOD):** A body composed of representatives from the Network area including at least one patient representative. The BOD (or executive committee) supervises the performance of the Network's administrative staff in meeting contract deliverables and requirements and maintains the financial viability of the Network.
- **Medical Review Board (MRB):** A body composed of at least one patient representative and representatives of each of the professional disciplines (physician, registered nurse, social worker, and dietitian) that is engaged in treatment related to ESRD and qualified to evaluate the quality and appropriateness of care delivered to ESRD patients.
- **Any other committees** necessary to satisfy requirements of the SOW. These committees are designated by the Network and/or BOD and may include, but are not limited to patient advisory, grievance, organ procurement, transplant, finance, and rehabilitation.

## HCFA NATIONAL GOALS AND NETWORK ACTIVITIES

The 1997 – 2000 Statement of Work outlines four goals to provide direction to the national ESRD Network program. These goals outline the basic functions of the ESRD Networks and are used to direct the Network daily activities. Each Network tailors its activities to meet and exceed HCFA expectations.

The four goals are:

1. Improving the quality of health care services and quality of life for ESRD beneficiaries;
2. Improving data reporting, reliability and validity between ESRD facilities/providers, Networks and HCFA;
3. Establishing and improving partnerships and cooperative activities among and between the ESRD Networks, Peer Review Organizations, State Survey Agencies and ESRD facilities and providers; and,
4. Evaluating and resolving grievances.

These goals and how the Networks accomplished them are discussed below.

## **GOAL ONE: IMPROVING THE QUALITY OF HEALTH CARE SERVICES AND QUALITY OF LIFE FOR ESRD BENEFICIARIES**

The Health Care Financing Administration (HCFA) contracts with the eighteen ESRD Networks to design and administer quality improvement/assurance programs. The structure and composition of the Networks place them in a unique position to accomplish this. The Networks are non-profit organizations, led by volunteer boards and committees of nephrology patients and professionals. HCFA outlines the broad expectations for the Networks and specifies certain projects and tasks in the ESRD Network Statement of Work (SOW). The geographic distribution of the eighteen Networks allows each to design projects most appropriate for the population served. The Networks can adapt projects for the different cultural and clinical needs of the area and take advantage of local resources to advance the project. With limited resources, Networks must determine which projects can have the broadest impact on improving quality. Networks share these project ideas with one another so successful projects can be repeated.

The Networks serve as a liaison between HCFA and ESRD providers and between the ESRD patients and providers. HCFA, providers and patients all have a vested interest in achieving optimal treatment. The Networks are a vital link in the quality chain. Networks accomplish their quality mission by:

1. Collecting and validating patient-specific clinical data in an environment exempt from the Freedom of Information Act (FOIA)
2. Distributing data feedback reports for facilities to use to improve care
3. Conducting quality improvement projects and activities, focused on specific areas of care
4. Providing professional educational materials and workshops for facility staff
5. Providing patient educational materials and workshops to facilities and directly to patients
6. Offering technical assistance to dialysis and transplant facilities

### **COLLECT AND VALIDATE PATIENT-SPECIFIC CLINICAL DATA IN AN ENVIRONMENT EXEMPT FROM THE FREEDOM OF INFORMATION ACT (FOIA)**

The Consolidated Omnibus Budget Reconciliation Act (COBRA) of 1989 amended Section 1881(c) of the Social Security Act to provide liability protection for ESRD Networks and prohibition against disclosure of information. Section 1160 states that the Network “in carrying out its functions under a contract entered into under this part, shall not be a Federal agency for purposes of section 552 of title 5, United States Code (commonly referred to as the Freedom of Information Act). Any data or information acquired by any such organization in the exercise of its duties and functions shall be held in confidence and shall not be disclosed to any person except 1) to the extent that may be necessary to carry out the purposes of this part, 2) in such cases and under such circumstances as the Secretary shall by regulations provide to assure adequate protection of the rights and interests of patients, health care practitioners, or providers of health care or 3) in accordance with subsection (b).” Subsection (b) describes reporting the Secretary might require.

This legislation allows Networks to collect patient-specific and facility-specific data in a protected quality improvement environment. Some of the descriptive and demographic data collected by Networks is copied to HCFA and is releasable in limited forms, according to HCFA policies. Data collected for quality projects, is protected from release and re-release. Networks believe this contributes to the cooperation of facilities to submit data and to the high accuracy of data at the Network.

**Table 7  
DESCRIPTIVE AND QUALITY DATA COLLECTED  
BY NETWORKS AS REQUIRED BY CONTRACT**

Demographic/Descriptive		
Standard HCFA Forms	HCFA-2728: Medical Evidence HCFA-2746: Death Notification HCFA-2744: Annual Facility Survey	Demographics and pre-ESRD clinical data for all new ESRD patients Date and cause of death Reconciliation of patient activity
Minimum Data Set – No Standard Forms	Non-Clinical Patient Events Facility Characteristics and staff	Allows Networks to place patient on any given day by treatment center and type of modality Size, ownership, staffing
Quality Improvement		
Standard HCFA Clinical Performance Measures	HCFA-820: Hemodialysis CPM Form HCFA 821: Peritoneal dialysis CPM Form No number: Facility CPM Form	Clinical indicator forms collected once per year on a sample of patients in each Network.
Infectious Disease	National Surveillance of Dialysis Associated Diseases	Facility-specific outcomes and practices

**National Clinical Performance Measures (CPM) Project**

Formerly known as the National Core Indicators Project, the collection and reporting of this data collection provides the backbone of many of the Network quality improvement activities. It provides important feedback of outcomes measurement at the national and Network level. HCFA has identified four quality indicators for this project:

- Adequacy of Dialysis
  - Hemodialysis: URR and Kt/V
  - Peritoneal Dialysis: Kt/V and Creatinine Clearance
- Nutritional status
  - Albumin
- Anemia Management
  - Hematocrit and Hemoglobin
- Vascular Access
  - Hemodialysis only

Each year, HCFA (or its contractor) draws a random 4% sample of adult (age≥18 years) ESRD dialysis patients and Networks prepare and distribute the collection forms. Facilities report hemodialysis data for the last quarter of the previous year and peritoneal dialysis data for the last quarter of the previous year and first quarter of the current year. In 1999, Networks collected 8,336 hemodialysis forms and 1,533 peritoneal dialysis forms.

When forms are complete, Networks enter the data into standard software and submit the data to HCFA for analysis. The Networks then conduct a validation of the data, based on 5% of the original sample.

The results of the CPM project are described below.

### Geographic Network Adaptations:

The Clinical Performance Measures project provides national- and Network-specific rates for quality indicators. The sample size is not large enough to provide facility-specific reporting. Many Networks have chosen to collect clinical indicators on a broader sample to have facility-specific outcomes measures. Methods used for this include:

- 100% of patients from 100% of facilities
- Sample of patients from 100% of facilities
- Aggregate facility data from 100% of facilities

## **DISTRIBUTE DATA FEEDBACK REPORTS FOR FACILITIES TO USE TO IMPROVE CARE**

All Networks distribute the following data feedback reports to dialysis and/or transplant facilities:

- Annual Report of Network activities and accomplishments
- National Clinical Performance Measures report
- Unit Specific Reports of standardized mortality, morbidity and other rates, produced by University of Michigan
- Center for Disease Control National Surveillance of Dialysis Associated Diseases Report
- Miscellaneous data requests by facilities
- Forms compliance reports

### **National Clinical Performance Measures (CPM) Project**

The collection and validation of CPM data is described above. After Networks have collected, entered, validated and transmitted the data, HCFA performs an analysis and produces an Annual Report of the Project. HCFA distributes the report to every dialysis facility and Networks receive a supply to distribute as needed. More information on this can be found online at <http://www.hcfa.gov/quality/3m.htm>.

HCFA uses the CPM data to assess the quality of care being delivered to Medicare beneficiaries and to evaluate the effectiveness of the Network programs in improving care. Networks use the report, in combination with other feedback reports, to select areas for quality improvement/assessment projects and activities. A summary of the findings is presented here.

### **ADEQUACY OF DIALYSIS: HEMODIALYSIS**

- Mean URRs have increased each year that data have been collected (62.7% in 1993 to 68.2% in 1998)
- In 1998, the percent of patients with a  $Kt/V \geq 1.2$  varied by Network and ranged from 74% to 87%
- 80% of patients in 1998 had a mean delivered dialysis with a  $Kt/V \geq 1.2$

### **ADEQUACY OF DIALYSIS: PERITONEAL DIALYSIS**

- Adequacy of dialysis was assessed during the study period for an estimated 85% of patients, an increase from 81% in 1997
- 55% of CAPD patients had mean weekly  $Kt/V \geq 2.0$  and creatinine clearance  $\geq 60$  L/wk/1.73m<sup>2</sup>
- 45% of cycler patients had mean  $Kt/V \geq 2.2$  and mean weekly creatinine clearance  $>66$  L/wk/1.73m<sup>2</sup>



**ANEMIA MANAGEMENT: HEMODIALYSIS**

- Mean hematocrit increased from 31.9% in 1995 to 34.4% in 1998
- The percent of patients in 1998 with a mean hemoglobin  $\geq 11$  gm/dL ranged by Network from 50% to 68% with a national average of 59%
- 65% of patients in 1998 had a mean hematocrit  $\geq 33\%$

**ANEMIA MANAGEMENT: PERITONEAL DIALYSIS**

- The percentage of patients with a mean hemoglobin  $>10$  gm/dL increased from 76% in 1997 to 82% in 1998
- The average hematocrit in 1995 was 32.5%, rising to 34.5% in 1998
- 72% of patients had a transferrin saturation  $\geq 20\%$  and at least one documented serum ferritin concentration  $>100$  ng/mL.

**SERUM ALBUMIN: HEMODIALYSIS**

- Mean serum albumin values in 1998 bromocresol green (BCG) laboratory method was 3.8 gm/dl, unchanged from 1997
- Mean serum albumin values determined by bromocresol purple (BCP) laboratory method was 3.6 gm/dl, also unchanged from 1997
- Percent of patients with mean serum albumin values  $> 3.5$  gm/dl by BCG or  $> 3.2$  gm/dl by BCP varied by Network from 72% to 85%

**SERUM ALBUMIN: PERITONEAL DIALYSIS**

- The mean serum albumin values in 1998 for peritoneal dialysis patients were 3.5 gm/dl by BCG method and 3.3 gm/dl by BCP method, unchanged from 1997
- The percent of patients with mean serum albumin by BCG method increased in 1998 to 58% from 54% in 1997. The mean serum albumin by BCP method increased in 1998 to 65% from 60% in 1997

**VASCULAR ACCESS: HEMODIALYSIS ONLY**

- 26% of the surviving 1998 incident patients had an arterial venous fistula (AVF)
- 26% of all prevalent patients for the same time period had an AVF. Routine monitoring for stenosis during October – December 1998 was done on 37% of the patients with AVF.

**Additional Reports and Geographic Network Adaptations of Data Feedback**

Additional reports that Networks have developed for their region include:

- Facility-specific outcomes measure reports
- Physician-specific outcomes measures reports
- Standardized mortality rates, adjusted locally
- Self care rates compared to Network
- Transplant referral rates compared to Network
- Facility practices compared to others in Network

## CONDUCT QUALITY IMPROVEMENT PROJECTS AND ACTIVITIES, FOCUSED ON SPECIFIC AREAS OF CARE

### Quality Improvement Projects

The ESRD Network contract with HCFA requires completion of at least one Quality Improvement Project (QIP) per year. This is a formal project for which HCFA has defined the format and selected areas for improvement:

- Adequacy of Dialysis
- Anemia
- Vascular Access
- Preventive Health Care (flu and hepatitis vaccination)

Network Medical Review Boards (MRB) review available data profiles to select an appropriate area and specific focus for the QIP. With HCFA approval, Networks may select alternate topic areas for their QIP. The QIP format requires each Network to define the method, outcome and process indicators, intervention and evaluation. The table below briefly summarizes the 1999 projects; complete reports are available from each Network.

**Table 8**  
**1999 NETWORK QUALITY IMPROVEMENT PROJECTS**  
**(Includes projects begun and/or completed in 1999)**

Network	Project	Status at December 1999
<b>ADEQUACY OF DIALYSIS – HEMODIALYSIS</b>		
<b>4</b>	<ul style="list-style-type: none"> <li>• Increase dialysis delivery so actual delivered dose equals prescribed</li> </ul>	Outcome goal met: Delivered dose of dialysis increased. Changes in process measures not significant, but did produce desired outcome.
<b>5</b>	<ul style="list-style-type: none"> <li>• Improve the adequacy of dialysis delivered</li> <li>• Improve the adequacy of prescribed treatment</li> <li>• Improve delivery of dialysis prescription</li> </ul>	Improvement demonstrated in all areas. Most profound improvement was in the adequacy of prescribed treatment.
<b>8</b>	<ul style="list-style-type: none"> <li>• Improve outcomes in 13 facilities with facility mean URR below 65% and 40% or greater of patients with URR below 65%</li> </ul>	Project continued into 2000.
<b>11</b>	<ul style="list-style-type: none"> <li>• Improve percent of patients with URR <math>\geq</math> 65%</li> </ul>	Increased to 78.4% of patients with URR $\geq$ 65%. Will continue to work to improve
<b>13</b>	<ul style="list-style-type: none"> <li>• Improve the adequacy of dialysis delivered</li> <li>• Improve the adequacy of prescribed treatment</li> <li>• Improve delivery of dialysis prescription</li> </ul>	4% increase towards achieving adequate hemodialysis via prescriptions. Adherence to prescription was shown in nine of the ten facilities.
<b>17</b>	<ul style="list-style-type: none"> <li>• Increase percent of patients with URR greater than or equal to 65%</li> <li>• Eliminate/reduce barriers to adequate dialysis</li> </ul>	Of 12 facilities randomly selected for intensive assessment, all had incomplete treatment documentation in the chart. By the end of the project, all facilities were using or

<b>Network</b>	<b>Project</b>	<b>Status at December 1999</b>
	<ul style="list-style-type: none"> <li>Evaluate URR vs Kt/V and variances of occurring with these measures</li> </ul>	planning to use Kt/V for adequacy assessment. Interventions continued into 2000.
<b>ADEQUACY OF DIALYSIS – PERITONEAL DIALYSIS</b>		
2	<ul style="list-style-type: none"> <li>Increase the percentage of patients with adequacy measures performed</li> <li>Improve the outcomes of the adequacy measurements</li> </ul>	Continued into 2000
5	<ul style="list-style-type: none"> <li>Increase number of facilities measuring adequacy by method and frequency recommended by DOQI</li> <li>Increase the number of prescription changes in response to low adequacy values</li> </ul>	Continued into 2000
6	<ul style="list-style-type: none"> <li>Increase the percentage of patients with adequacy measures performed</li> <li>Improve the outcomes of the adequacy measurements</li> </ul>	Percentage of patients with adequacy measures increased significantly. Creatinine clearance outcomes improved for CCPD and CAPD (significantly).
8	<ul style="list-style-type: none"> <li>Improve protocols and prescriptions in 15 facilities targeted for improvement</li> <li>Improve KT/V and Creatinine clearance</li> </ul>	All facilities showed improvement in KT/V with 9 being statistically significant. Seven facilities improved creatinine clearance. All facilities decreased the number of patients falling below both marks, six of them significantly.
9/10	<ul style="list-style-type: none"> <li>Increase the percentage of patients with adequacy measures performed</li> <li>Improve the outcomes of the adequacy measurements</li> </ul>	Preliminary analysis shows correlation between measurement frequency and outcome. Project continued into 2000.
15	<ul style="list-style-type: none"> <li>Increase the percentage of patients with adequacy measures performed on a timely basis</li> <li>Improve the outcomes of the adequacy measurements</li> </ul>	Improvement shown in number of patients with a completed Kt/V (69.9% to 80.4%). Of the 24% with inadequate dialysis, 46% experienced a prescription change.
<b>ANEMIA</b>		
3	<ul style="list-style-type: none"> <li>Partnered with national chain to reduce variation in anemia management and outcomes</li> </ul>	10 of 15 intervention facilities showed statistically significant improvement in number of patients with hematocrits greater than 33%
11	<ul style="list-style-type: none"> <li>Improve percent of patients with hgb <math>\geq</math> 11</li> </ul>	Increased to 65% of patients with hgb $\geq$ 11. Will continue to work to improve.
17	<ul style="list-style-type: none"> <li>Increase the proportion of hemodialysis patients with hematocrit &gt; 31%</li> <li>Decrease proportion of hemodialysis patients with hematocrit less than or equal to</li> </ul>	Average Network hematocrit rose from 31.9% to 33.8% and percent of patients with hematocrit below 25% dropped from 6% to 0.2%. Ninety-five percent (95%) of facilities had an Epogen protocol that was followed effectively. 65% of facilities changed their

<b>Network</b>	<b>Project</b>	<b>Status at December 1999</b>
	25% <ul style="list-style-type: none"> <li>• Improve management of anemia</li> <li>• Prepare facilities to meet new targets of clinical performance measures</li> </ul>	Epogen protocol in response to proposed HMA changes.
<b>VASCULAR ACCESS</b>		
<b>1</b>	<ul style="list-style-type: none"> <li>• Determine variation in initial access</li> <li>• Explore relationship of 1<sup>st</sup> access and length of time patient known to be ESRD</li> </ul>	Continued into 2000
<b>3</b>	<ul style="list-style-type: none"> <li>• Increase prospective monitoring of AV grafts to decrease thrombosis incidence</li> </ul>	Problems arose with Medicare not reimbursing necessary tests. Project continued into 2000.
<b>4</b>	<ul style="list-style-type: none"> <li>• Increase primary care physician awareness of importance of early referral</li> <li>• Increase placement of primary AV fistula or synthetic bridge graft at least 30 days prior to dialysis</li> </ul>	Continued into 2000
<b>7</b>	<ul style="list-style-type: none"> <li>• Increase the use of AV fistulas as the primary choice for hemodialysis vascular access</li> </ul>	Continued into 2000
<b>9/10</b>	<ul style="list-style-type: none"> <li>• Lower the central venous catheter rate</li> </ul>	Standardized catheter rates less than 1.0 decreased from 18% to 10% and Standardized fistula rates greater than 1.0 increased from 13% to 18%
<b>11</b>	<ul style="list-style-type: none"> <li>• Improve earlier referrals from the primary care physician to the nephrologist and from the nephrologist to the vascular access surgeon.</li> </ul>	27% of incident patients began dialysis using a catheter even though they were referred to a Nephrologist >1 month before HD. Results were published October 2000, and work continues. Publication of final results planned for 2000.
<b>13</b>	<ul style="list-style-type: none"> <li>• Improve early detection of venous stenosis</li> <li>• Increase appropriate referral for AVG-specific intervention</li> </ul>	Awaiting analysis of HCFA claims data. Intervention to begin in 2000.
<b>14</b>	<ul style="list-style-type: none"> <li>• Decrease utilization of catheters for permanent vascular access</li> </ul>	Two-year project, continued into 2000.
<b>16</b>	<ul style="list-style-type: none"> <li>• Reduce the rate of hemodialysis access infections</li> </ul>	Continued into 2000.
<b>18</b>	<ul style="list-style-type: none"> <li>• Increase the number of AV fistulae to 50% for incident patients and 40% for prevalent patients</li> </ul>	Continued into 2000
<b>PREVENTIVE HEALTH CARE (FLU AND HEPATITIS VACCINATION)</b>		
<b>1</b>	<ul style="list-style-type: none"> <li>• Increase the number of patients receiving flu shot</li> </ul>	In 1997, only 34% of facilities had a written Influenza Immunization policy. By end of 1999, 98% had written policies.
<b>4</b>	<ul style="list-style-type: none"> <li>• Increase proportion of patients informed about flu</li> </ul>	Document the actual number of ESRD beneficiaries who were immunized

<b>Network</b>	<b>Project</b>	<b>Status at December 1999</b>
		regardless of location of immunization.
<b>5</b>	<ul style="list-style-type: none"> <li>• Increase the number of patients receiving flu shots</li> <li>• Increase the number of facilities offering flu shot at the clinic</li> </ul>	On-going project. Increase in immunization rates shown in 1996 and 1997. Decline noted in 1998. 1999 data analysis continued into 2000.
<b>6</b>	<ul style="list-style-type: none"> <li>• Increase the number of patients receiving flu shot</li> </ul>	On-going project. Immunization rates have improved every year since project began in 1997
<b>12</b>	<ul style="list-style-type: none"> <li>• Increase the percent of patients immunized against Hepatitis B Virus (HBV) infection</li> </ul>	Statistically significant improvement was shown from baseline measurement to final survey. (66.9% to 73.2%)
<b>14</b>	<ul style="list-style-type: none"> <li>• Increase number of patients vaccinated annually against influenza, every 5 years for pneumococcal and HBV per CDC recommendations</li> <li>• Reduce incidence of influenza, pneumonia and hepatitis B</li> <li>• Decrease patient mortality and morbidity from I-P-H and reduce hospital and associated medical costs</li> </ul>	Network survey data, previously shown to be reliable and reproducible, showed improvement in both the percent of facilities offering and the percent of patients accepting immunizations. Two sources of data were used to evaluate the project (Medicare billing data and Network-specific survey). Inconsistencies were shown and HCFA notified regarding the low level of beneficiary immunization billing of Medicare.
<b>15</b>	<ul style="list-style-type: none"> <li>• Compare number of Medicare-billed influenza immunizations to actual number</li> <li>• Identify barriers to ESRD patients receiving immunization</li> <li>• Assure that facility inability to bill Medicare was not a barrier to patients receiving immunization</li> </ul>	74.6% of patients immunized, exceeding HCFA Healthy People 2000 Objective. Medicare billing data shown to underreport immunization rate (only 37.8% reported immunized). Project continued to reach Network immunization goal of 90%.
<b>18</b>	<ul style="list-style-type: none"> <li>• Improve the Hepatitis B vaccination rate to at least 50%</li> </ul>	Immunization rate rose from 14% in 1994 to 36% in 1998. In 1996, only 16% of facilities had at least 50% of patients immunized. In 1998 this rose to 59%. In 1996, 47% had no patients immunized. By 1998, this had dropped to only 1.5%. 1999 remeasurement to be performed early 2000.
<b>DIABETES CARE (NETWORK-DEFINED AREA OF CARE)</b>		
<b>2</b>	<ul style="list-style-type: none"> <li>• Raise physician/facility awareness of diabetes management of ESRD patients</li> </ul>	Continued into 2000

Source: Networks 1-18 Annual Reports, 1999

### **Quality Improvement Activities**

In addition to formal Quality Improvement Projects (QIP), Network Medical Review Boards (MRB) also design quality assessment and improvement activities to address areas of concern. These may be specific to the Network area and include individual approaches. In 1999, Networks conducted many quality activities, some of which are highlighted below.

**Table 9**  
**HIGHLIGHTS OF 1999 QUALITY ASSESSMENT/IMPROVEMENT ACTIVITIES**

<b>Network</b>	<b>Project</b>	<b>Overview</b>
<b>1</b>	Hemodialysis Bacteremia Surveillance	Monitor and provide feedback on bacteremia rates
<b>1,4,11</b>	Prioritization of NKF KDOQI Guidelines	Determine clinical practice guidelines of highest priority and develop CQI tools for these priorities
<b>4</b>	Development of a Pediatric Database	Develop data collection tool to monitor overall growth and development of pediatric ESRD patients. Over time, outcome data may establish adequacy of dialysis guidelines. Revisions made to form after pilot test. The first data collection occurred November 1999.
<b>4</b>	Transplant Poster	Transplant poster designed by a Patient Advisory Committee member was distributed to dialysis facilities for patient information. Poster designed to encourage dialysis patients to consider transplantation; common questions were answered on the poster.
<b>5</b>	Transplant Project	Increase educational efforts to promote living donor kidney transplant
<b>5</b>	Vancomycin Resistant Enterococcus (VRE) Project	Determine frequency of bacterial infections, incidence and prevalence of VRE colonization and the risk factors for bacterial infection and VRE. Pilot test a method to track infection rates, I antimicrobial starts, vancomycin use and number of hospital admissions per month. Provide method of delivering information to CDC for analysis.
<b>5</b>	Quality Awards	Presented awards to 22 facilities demonstrating outstanding quality in selected clinical areas
<b>5,8,11,18</b>	Cooperative National Study of Renal Decisions (CONSORD)	Evaluate modality selection and transplant referral rates
<b>6</b>	Focused Review	Intense intervention with facilities chosen based on clinical outcomes
<b>7</b>	Transplant Rate Improvement Project	Identify interventions for improving transplant rates, focusing in 1999 on using a dialysis facility designee to coordinate patient referrals
<b>7</b>	Exercise Program	Demonstration project to assess the problems and benefits in ESRD facility-based exercise programs
<b>8</b>	Working with Challenging Patients Situations	Six regional workshops were supplied to all Network facilities.
<b>9/10</b>	Intervention Profiling System	Intense intervention with facilities chosen based on clinical outcomes, grievances and cooperation with Network goals
<b>11</b>	Prevention And Treatment Of Renal Osteodystrophy	Collect Ca, Phos, and 1 PTH data; develop model protocol; review facility protocols; and conduct prescription survey.
<b>11</b>	Elab	Download lab data electronically from laboratories to generate facility – specific comparative profiles.
<b>13</b>	Quality Performance	Intense intervention with facilities with lower than

<b>Network</b>	<b>Project</b>	<b>Overview</b>
	Measures	average outcomes.
<b>14</b>	Criteria and Standards	Developed to guide facility practice and provide standards for medical review decisions and grievance investigations
<b>14</b>	Comparison Of Facility Standardized Mortality Rate And Regulatory Survey Outcomes	After analysis, MRB recommended against use of SMR data to select facilities for survey.
<b>15</b>	Pre-dialysis Care Project	Demonstrate feasible method for describing key aspects of pre-dialysis care and determine opportunities to improve care for these patients
<b>16</b>	Standardized Mortality Ratio Intervention	Intense facility monitoring/intervention based on outcomes significantly higher than average
<b>17</b>	Pacific Islands Core Indicators Follow Up Project	Intensive intervention to reduce variation in practice and improve outcomes of care.
<b>17</b>	Hepatitis B Vaccination Information Campaign	Distribution of materials to promote the use of the new mandatory Vaccination Information Statements for Hepatitis B
<b>17</b>	Organizational Standards of Care	Adapted standards from Joint Commission on Accreditation of Healthcare Organizations for ESRD
<b>18</b>	Heparinization Practices Project	Reduce the amount of heparin administered by educating facility staff on dosing methods
<b>18</b>	Emergency call system project	Investigate prevalence of chair-side emergency call systems in hemodialysis facilities

Source: Networks 1-18 Annual Reports, 1999

### **PROVIDE PROFESSIONAL EDUCATIONAL MATERIALS AND WORKSHOPS FOR FACILITY STAFF**

The principles of quality improvement require that the healthcare team, not HCFA or its agents, identify the opportunity for improvement and develop the appropriate intervention. ESRD Networks are a vital resource to facilities, providing educational materials and workshops. The Networks develop their own materials and serve as a clearinghouse for materials developed by others. These materials are distributed in hard copy, posted on Network websites, sent via email and broadcast fax. Under contract with HCFA, Networks are to provide, at a minimum, the following materials:

1. HCFA ESRD Network goals, the Network activities conducted to meet these goals, and the Network's plan for monitoring facility compliance with the goals;
2. The Network's Annual Report;
3. Regional patterns or profiles of care as provided in the Core Indicators Annual Report;
4. Results of Network Quality Improvement Projects;
5. Other material (such as journal articles or pertinent research information) that providers/facilities can use in their quality improvement programs;
6. The process for handling patient grievances;
7. Treatment options and new ESRD technologies available for patients; and
8. State/regional vocational rehabilitation program available in the Network area.

**Table 10**  
**1999 HIGHLIGHTS OF PROFESSIONAL EDUCATION WORKSHOPS**  
**AND PROGRAMS OFFERED BY NETWORKS**

<b>CLINICAL</b>
• “Homocysteine and Vascular Disease”
• Homocysteine, Vitamins and the Dialysis Patient
• Improving the Delivery of Adequate Dialysis
• The Challenge of Phosphorus Control
• Advances in Immunosuppression
• New Iron Management Strategies
• Strategies for optimizing the use of the AV Fistula
• Six Barriers to Adequate Dialysis
• Vascular Access Team Perspectives
• Anemia Management
• Diagnostic and therapeutic problems with vascular access
• Antimicrobial resistance in dialysis facilities
• Herbal remedies impact on dialysis patients
• Non-nutritional causes of hypoalbuminemia
<b>PATIENT RELATED</b>
• “Ethical issues of Dialysis Termination”
• Adequate Dialysis: What Every Patient should Know and How patients Can help
• AAKP Patient Plan
• Importance of Patient Education
<b>COMMUNICATION/CRISIS MANAGEMENT</b>
• Conflict resolution workshops
• Crisis Prevention Training
• Overview of CPI Non-Violence Crisis Intervention Training
• Creating a Positive Climate in Healthcare
• Meeting the Needs of Challenging Patients
• Improving Communication Skills
<b>PSYCHOSOCIAL/REHABILITATION</b>
• “Geriatric Considerations, Practice Guidelines and Quality of Life Assessments”
• Nursing home workshops for administrators of nursing homes providing dialysis
• Finding your Way through the Medicare Maze
• Medicare Issues and Anemia Workshop
• Management and treatment of depression
• Renal Exercise
• Emergency planning
• Advanced psychiatric assessment of ESRD patients
• RPA/ASN guidelines on shared decision making in the appropriate initiation and withdrawal from dialysis
• Vocational Rehabilitation issues
• Review of LORAC Program Resources
<b>CQI</b>
• CQI from Concept to Practice
• Applying CQI to Dialysis Care



•	The Challenge of Change
•	Living Donor Kidney Transplant Quality Improvement Project
•	ANNA Standards and Guidelines or Clinical Practice
•	QIP Interventions
<b>GENERAL</b>	
•	Year 2000 (Y2K) Preparation
•	Everything You Wanted to Know about the Network (but didn't know who to ask)"
•	"Implications of Pennsylvania Act 102"
•	New Ways of Viewing the Business of ESRD: Outcomes, Economics and Alliances
•	Legal requirements of chart documentation
•	What's on the Front Burner at HCFA
•	Overview of NKF DOQI nutrition guidelines
•	SIMS-Standardized Information Management System
•	Methods to improve survey outcomes
•	Overview of Renal Disease Management Organizations

Source: Networks 1-18 Annual Reports, 1999

The list of materials distributed by Networks is too extensive to itemize. Highlights of the materials developed and/or distributed in 1999 include:

**Table 11**  
**1999 HIGHLIGHTS OF PROFESSIONAL EDUCATION MATERIALS DEVELOPED**  
**AND/OR DISTRIBUTED BY NETWORKS**

<b>CLINICAL</b>
• FDA Safety alert on Urokinase
• FDA Safety alert on Transducer Filters
• Information on "Rinse-back procedures when terminating a dialysis session
• Extracorporeal re-circulation
• Intradialytic Parenteral Nutrition
<b>GUIDELINES/REGULATORY</b>
• State dialysis regulations
• Advanced practice nurses in nephrology settings
• Dialysis in the operating room setting
• Emergency generator regulations
• Medicare regulations
• OSHA regulations
• Water quality testing reference materials
<b>PATIENT RELATED</b>
• Model long term care plan
• Advance Directives
• Ambulance transportation
• Brochure to promote PD patients' compliance with dialysis prescription and adequacy measurements
• Sample treatment agreements
• Manual for caring for patients with special needs
<b>CQI</b>
• CQI resources/articles
<b>GENERAL</b>
• Facility newsletters
• Network posters displayed at regional and national meetings
• Information on kinetic modeling techniques and assessing adequacy of dialysis

Source: Networks 1-18 Annual Reports, 1999

**PROVIDE PATIENT EDUCATIONAL MATERIALS AND WORKSHOPS TO FACILITIES AND DIRECTLY TO PATIENTS**

ESRD Networks also develop and serve as a clearinghouse for patient education materials. Some of these are sent directly to the patient; others are distributed to the facility for use in its patient education efforts. Most Networks have toll-free phone numbers for patients and respond to numerous requests for patient assistance.

**Table 12**  
**1999 HIGHLIGHTS OF PATIENT EDUCATION MATERIALS/WORKSHOPS**  
**PROVIDED BY NETWORKS**

<b>GENERAL</b>
• Year 2000 (Y2K) preparedness
• Pharmaceutical coverage
• Patient Newsletters
• Requests for Network clearinghouse booklets, videos, etc
• Patient manuals, covering treatment options, medications, etc
• Adventure Park, a board game
• Pre-dialysis education resources
• Pediatric resources
• Living Well on Old Video (adherence to treatment)
<b>ACCESS TO CARE</b>
• Assistance with transient dialysis space
• Assistance with permanent dialysis space
• Transportation issues
• Listing of dialysis units in United States
<b>EMERGENCY ASSISTANCE</b>
• Emergency financial assistance referrals
• Disaster planning
<b>CLINICAL</b>
• Vascular Access video
• Infection control questions
• “What’s your ACCESS – ability?”
• Living Well on HD Video adherence to treatment
<b>PSYCHOSOCIAL/REHABILITATION/EXERCISE</b>
• Exercise Guide
• Quality of Life materials
• Living wills
• Patient Self-Determination Act
• Diet guide for the Hemodialysis Patient
• Religious Faiths and Transplantation
• Patient and/or spouse support group resources
• Patient rights and responsibilities
• Nutritional information
• Some successful home remedies for itching associated with renal failure

Source: Networks 1-18 Annual Reports, 1999

**GOAL TWO: IMPROVING DATA REPORTING, RELIABILITY AND VALIDITY  
BETWEEN ESRD FACILITIES/PROVIDERS, NETWORKS AND HCFA**

To accomplish the second goal, Networks utilize both internal and external databases to track various data. Data reporting is an essential function of the Networks. Accurate data collection has a two-fold purpose:

1. Aids the Networks by providing a look at issues facing the regional ESRD population and a check-system to measure facility accuracy and timeliness;
2. Provides the national ESRD data system with accurate data to support quality improvement initiatives, HCFA policy decision and the USRDS research activities.

Recognizing the need to standardize each ESRD Network’s data system, HCFA began working with the Networks and Forum of ESRD Networks to accomplish this standardization. In October of 1997, the Southeastern Kidney Council (Network 6) was awarded a 24-month contract to design, develop, and install Standard Information Management System (SIMS). The purpose of the project is to design, develop, purchase and install a standard information management system that supports the ESRD Network Organizations. It also provides communication and data exchange links among the Networks, HCFA, and other segments of the renal community to support quality improvement activities that relate to the treatment of ESRD. Throughout 1998, Networks began shaping the project through established workgroups to determine core data set elements, security issues and a standardized data dictionary. Two Networks, Network 5 and Network 6, began Alpha testing SIMS in November 1998. Beginning in June 1999, Networks 5,6,7,11, 13 and 15 conducted Beta testing for a 6 – month period. SIMS was released in December 1999 (Southeastern Kidney Council 1998 Annual Report). While SIMS is being used by all Networks, development and enhancements continue to be made to the software.

SIMS allows each Network to support and maintain its own database to store patient specific information and ESRD related events. On a broad level, these databases maintain demographic data as well as track patient transactions such as changes in modality, facility, transplant status, or death. In this manner, Networks are able to maintain accurate counts of patients within their area. The information tracked within Network databases is collected from the ESRD provider through the Medical Evidence Report Form (HCFA 2728) and the Death Notification Form (HCFA 2746). Providers are responsible for submitting these documents in an accurate and timely manner. Networks monitor providers based on their data submission practices and are responsible for addressing non-compliance. Other clinical data elements are also retained in their Network database for quality improvement activities.

Networks are also responsible for transmitting these data to HCFA using the SIMS data entry capability. Each month, Networks transmit information collected to the HCFA database. Table 13 shows the number of forms collected by Networks in 1999.

**Table 13  
DATA FORMS PROCESSED  
Calendar Year 1999**

<b>Network</b>	<b>Medical Evidence (HCFA 2728)</b>	<b>Death Notification (HCFA 2746)</b>	<b>Total</b>
<b>1</b>	3,804	2,662	6,466
<b>2</b>	6,354	4,969	11,323
<b>3</b>	4,295	5,426	9,721
<b>4</b>	4,663	3,162	7,825
<b>5</b>	5,633	3,738	9,371

<b>6</b>	7,045	4,536	11,581
<b>7</b>	5,574	4,026	9,600
<b>8</b>	4,934	3,568	8,502
<b>9</b>	6,335	3,865	10,200
<b>10</b>	3,557	2,017	5,574
<b>11</b>	6,189	4,360	10,549
<b>12</b>	4,009	2,733	6,742
<b>13</b>	3,887	2,836	6,723
<b>14</b>	7,338	4,279	11,617
<b>15</b>	3,953	2,358	6,311
<b>16</b>	2,553	1,739	4,292
<b>17</b>	4,565	2,774	7,339
<b>18</b>	6,807	3,252	10,059
<b>Total</b>	<b>91,495</b>	<b>62,300</b>	<b>153,795</b>

Source: Networks 1-18 Annual Reports, 1999

In building this information infrastructure, the Networks hope to better pursue initiatives to measure and improve the quality of healthcare delivered to the ESRD patient population. The ultimate goal of SIMS is to improve the quality of care delivered by making ESRD data more accessible to dialysis facilities, Networks and the renal community.

**GOAL THREE: ESTABLISHING AND IMPROVING PARTNERSHIPS AND COOPERATIVE ACTIVITIES AMONG AND BETWEEN ESRD NETWORKS, PEER REVIEW ORGANIZATIONS (PROS), STATE SURVEY AGENCIES AND ESRD FACILITIES AND PROVIDERS**

Networks participate in a number of activities with organizations facilitating cooperation and joint ventures to fulfill this goal. Each Network creates unique partnerships with organizations to help provide better care for the ESRD patient population.

All Networks provide support and leadership to the Forum Clearinghouse of ESRD Networks. Network MRB Chairmen and Board members, Executive Directors, and other staff members assist the Forum by volunteering for positions on the Forum Clearinghouse Board of Directors as well as on various Forum Clearinghouse committees.

The Forum Clearinghouse, as a result of the participation of all 18 Networks, has been instrumental in developing and promoting a number of national initiatives that improve partnerships within the Network system. These include the SIMS initiative, the semi-annual meetings of MRB Chairpersons, development of a strategic plan, quarterly conference calls among the Executive Directors, and distribution of clearinghouse materials to all Networks.

The Forum Clearinghouse received several contract modifications from HCFA to assist in serving the Networks more efficiently. Through these contracts The Forum Clearinghouse arranged the spring meeting between HCFA representatives and the Networks. The meeting drew representatives from HCFA, Network staff from their Data, Quality and Executive departments as well as many Network Medical Review Board Chairmen to discuss issues impacting the ESRD Networks. The Forum Clearinghouse also received a contract modification to print and distribute the 1998 ESRD Core Indicators Data Collection Form as well as to format and distribute the Core Indicators Supplement and Highlight Reports.

The Forum Clearinghouse received a contract modification to organize a package of material that will be sent to every new ESRD patient, beginning September 2000. A committee composed of

staff from six community organizations (AAKP, ANNA, Life Options, NRAA, RPA, UNOS, and The Forum Clearinghouse) met and recommended the following to be included in the package: letter from HCFA explaining the packet to the patients, letter of introduction from the Network and a list of state agencies, *The Medicare Coverage of Kidney Dialysis and Kidney Transplant Services* (booklet), *AAKP Patient Plan-Phase I* (booklet), *Preparing for Emergencies: A Guide for People on Dialysis* (booklet) and a resource list of renal organizations.

In addition to working with the Forum Clearinghouse, Networks foster relationships with Peer Review Organizations (PROs). As seen below in Table 14, Networks implemented cooperative studies in conjunction with the PROs in the area of quality improvement during 1999. The projects varied from Network to Network but all projects focused on improving the care received by ESRD patients.

**Table 14**  
**1999 NETWORK-PRO COLLABORATION PROJECTS**

<b>Network</b>	<b>PRO</b>	<b>Topic or Project Name</b>
<b>1</b>	Connecticut Peer Review Association now known as Qualidigm	Coalition for Influenza and Diabetes
<b>2</b>	Island Peer Review Organization	Detection of Venous Stenosis
<b>4</b>	Keystone Peer Review Organization	Early Referral to Nephrology Care
<b>5</b>	Delmarva Foundation for Medical Care	Hemodialysis Adequacy Quality Improvement Project
<b>7</b>	Florida Medical Quality Assurance, Inc.	Hepatitis B Vaccination
<b>8</b>	Mid-South Foundation for Medical Care – Tennessee	Lower Extremity Amputation Prevention
<b>8</b>	Mississippi Foundation for Medical Care	Medicare Beneficiaries
<b>11</b>	North Dakota PRO	Pre-ESRD Conference
<b>11</b>	Minnesota PRO	Potential Projects for Collaboration
<b>12</b>	The Kansas Foundation for Medical Care The Iowa Medical Care Foundation Sunderbruch Corporation (Nebraska) Missouri Patient Care Review Foundation	Hepatitis B Vaccination
<b>13</b>	Louisiana Health Care Review	Vascular Access Monitoring
<b>13</b>	Oklahoma Foundation for Medical Quality	Diabetic Footcare in ESRD Facilities
<b>14</b>	Texas Medical Foundation	Be-Wise - Immunize !
<b>15</b>	Colorado Foundation for Medical Care	Peritoneal Dialysis Adequacy
<b>15</b>	Colorado and Mountain Pacific Quality Health Foundation	Pre-ESRD Care

Source: Networks 1-18 Annual Reports, 1999

Networks communicate with State Survey Agencies (SSAs) through the exchange of newsletters, annual reports, and other appropriate quality reports. This communication helps to facilitate the exchange of ideas on issues of quality improvement and patient grievances.

Networks continually communicate and coordinate activities with members of the renal community. In addition, they have fostered strong relationships with advocacy and research organizations. Some of the renal community Networks collaborate with are:

**AAKP:** American Association of Kidney Patients

<b>AKF:</b>	American Kidney Fund
<b>ANNA:</b>	American Nephrology Nurses Association
<b>ASN:</b>	American Society of Nephrology
<b>NKF:</b>	National Kidney Foundation
<b>NRAA:</b>	National Renal Administrators Association
<b>RPA:</b>	Renal Physicians Association
<b>PKF:</b>	Polycystic Kidney Foundation

Other organizations Networks work with include:

<b>CDC:</b>	Centers for Disease Control and Prevention
<b>FDA:</b>	Food and Drug Administration
<b>NAHQ:</b>	National Association for Healthcare Quality
<b>UNOS:</b>	United Network for Organ Sharing
<b>USRDS:</b>	United States Renal Data System
<b>AHQ:</b>	American Healthcare Quality Association
<b>LORAC:</b>	Life Options Rehabilitation Advisory Council
<b>AAMI:</b>	Association for Advancement of Medical Instrumentation

Many of the ESRD Network personnel are actively involved on renal community Boards of Directors and committees. The following are some of the organizations in the renal community with whom Networks serve on boards and committees: National Kidney Foundation (NKF) and the American Association of Kidney Patients (AAKP).

#### **GOAL FOUR: EVALUATING AND RESOLVING PATIENT GRIEVANCES**

Networks are responsible for evaluating and resolving patient grievances. Each Network has a formal grievance resolution protocol, approved by HCFA. The Network's ESRD Manual outlines several examples of the Network's role in resolving patient grievances. These include:

- **Expert Investigator:** This involves evaluating the quality of care provided to a patient where the investigation focus is the complaint. For example, if a patient complains about the procedures used by the dialysis nurse to initiate dialysis, the Network may investigate by reviewing the techniques used by the facility to initiate dialysis. At the conclusion of the investigation, findings are shared with the involved parties and, when appropriate, recommendations may be made about the care provided.
- **Facilitator:** When communication between the patient and the provider/facility is problematical, the Network may be asked to facilitate communication and resolve the differences. For example, a patient may contact the Network to complain that the facility hours do not accommodate his/her work schedule. The Network may assist the patient by helping to discuss the situation with the facility or assist the patient in moving to another facility that can accommodate his/her needs.
- **Referral Agent:** Issues which are not specifically ESRD Network issues such as fire safety, handicap access to dialysis, civil rights, infectious disease, and criminal activity are more appropriately handled by either the State Survey Agency or other Federal agencies. The Network may refer the beneficiary to the appropriate agency.
- **Coordinator:** Where both quality of care and survey and certification issues are involved (e.g., water quality or dialyzer reuse), the Network will coordinate the investigation with the appropriate State Survey Agency. The appropriate Regional Office is advised of the situation.

A formal beneficiary grievance is a documented complaint usually alleging that ESRD services did not meet professional levels of care. Networks request formal grievances to be submitted in writing, but all will address a grievance whether or not it is written. The formal complaint requires the Network to conduct a formal review of the information and an evaluation of the grievance, which may require the involvement of a Grievance Committee and/or the Medical Review Board. During 1999, Networks processed 86 formal beneficiary grievances. At least 30 grievances were referred to State Survey Agencies to be addressed either independently or in conjunction with the Network.

Grievances come to the Network in many forms, and from many sources including telephone calls and letters from patients, families, facilities, and patient advocates. Though many of these complaints never reach the formal grievance stage, Networks dedicate large amounts of staff time responding to these concerns. It is estimated that ESRD Networks process about 3,000 such patient concerns annually. The relatively small number of formal beneficiary grievances is an indication that Networks address most concerns before they become formal grievances.

Many Networks are focusing on assisting facility staff deal with challenging and noncompliant patients. Many have presented workshops on Crisis Prevention and programs to work with challenging patients as well as distribute educational materials and manuals with recommendations. These efforts are designed to assist the facility staff defuse potential problem situations in a professional and non-confrontational manner.

Table 15 displays the number and table 16 displays the type of formal written grievances filed in each Network during 1999. The Networks recognize the need to report in a similar manner and have developed a reporting system which has been incorporated into SIMS (Standard Information Management System). Current categories need refined definitions for inter-Network consistency. With such refinements, this system will make future reporting of patient concerns and grievances more consistent.

**Table 15**  
**FORMAL GRIEVANCES PROCESSED**  
**Calendar Year 1999**

<b>Network</b>	<b># of Grievances</b>	<b>Network</b>	<b># of Grievances</b>
1	1	11	0
2	0	12	6
3	0	13	0
4	1	14	10
5	7	15	0
6	18	16	0
7	12	17	0
8	10	18	4
9/10	17	<b>Total</b>	<b>86</b>

Source: Networks 1-18 Annual Reports, 1999

Table 16 groups grievances and concerns into broad categories based on their general type given their description in each Network's Annual Report. These categories also need further definition to improve consistency in reporting. The majority of the grievances relate to the patient's relationship to the staff and complaints regarding the staff or dialysis provider. The majority of the complaints lodged by facilities concern the handling of disruptive and abusive patients.



**Table 16**  
**TYPE OF GRIEVANCE**

<p>Treatment Related</p> <ul style="list-style-type: none"> <li>Any concern relating to the medical treatment a patient receives at the unit. These may include time of treatment, availability of treatment times, quality of treatment received, etc.</li> </ul>
<p>Physical Environment</p> <ul style="list-style-type: none"> <li>Any concern relating to the physical atmosphere of the unit. These may include temperature, cleanliness, hazards, etc.</li> </ul>
<p>Staff/Provider Related</p> <ul style="list-style-type: none"> <li>Any concern including difficulties with provider policies or staff such as professional behavior, competency, adherence to policy, etc.</li> </ul>
<p>Disruptive/Abusive Patient</p> <ul style="list-style-type: none"> <li>These complaints, lodged by the facility, concern how to handle a patient and/or family that is disruptive, abusive, or non-compliant.</li> </ul>
<p>Patient Transfer Related</p> <ul style="list-style-type: none"> <li>These relate to the inter-facility patient transfer process.</li> </ul>
<p>Transient Dialysis Related</p> <ul style="list-style-type: none"> <li>Any complaint concerned with the facility assisting the patient and/or family in identifying a provider for temporary dialysis treatment.</li> </ul>

Source: Networks 1-18 Annual Reports, 1999

## **SANCTION RECOMMENDATIONS**

Networks are authorized to propose (to HCFA) sanction recommendations against facilities who are out of compliance and to make recommendations for additional facilities in the service area, as they are necessary for each particular Network.

During 1999, only one sanction recommendation was made to HCFA. This sanction involved a facility in which the Network thought the practices did not meet the community standard of care over a period of time and in which the standardized mortality ratio was consistently higher than the average for the state in which the facility was located. The facility was not closed but was required to follow specific guidelines to monitor and improve deficiencies.

## **OTHER RECOMMENDATIONS**

There were Networks that made recommendations in their Annual Reports. These include:

- The need for a Medicare assessment of the costs to operate dialysis centers to include wage adjustments and local and state regulations to help with shortage of trained personnel.
- The need for HCFA to develop a billing code to accommodate the non-chronic, acute patients who require dialysis for an extended period of time. These patients do not need be hospitalized, but do require dialysis treatment until kidney function returns. Due to billing complications it is difficult to accommodate these patients in the traditional outpatient setting.
- The difficulty of providing ambulance transportation for hemodialysis patients in Skilled Nursing Facilities due to Medicare bundling costs.

- The need to increase transplantation services.
- The need to evaluate a mechanism for reimbursing acute care facilities adequately for treating patients who cannot be treated in chronic facilities due to behavioral problems.
- The need to establish special needs dialysis facilities to serve displaced patients.

## FOR MORE INFORMATION

This report summarizes highlights of ESRD Network's 1999 activities. The following Internet addresses provide additional information about the ESRD Networks and the ESRD program. All Network web sites can be access through the Forum's Clearinghouse home page, [www.esrdnetworks.org](http://www.esrdnetworks.org).

**Table 17**  
**NETWORK WEB ADDRESSES**

Network	Web Address
1	<a href="http://www.networkofnewengland.com">www.networkofnewengland.com</a>
2	<a href="http://www.esrdnetworks.org/networks/net2/net2.htm">www.esrdnetworks.org/networks/net2/net2.htm</a>
3	<a href="http://www.tarcweb.org">www.tarcweb.org</a>
4	<a href="http://www.esrdnetworks.org/networks/net4/net4.htm">www.esrdnetworks.org/networks/net4/net4.htm</a>
5	<a href="http://www.esrdnet5.org">www.esrdnet5.org</a>
6	<a href="http://www.esrdnetwork6.org">www.esrdnetwork6.org</a>
7	<a href="http://www.esrdnetworks.org/networks/net7/net7.htm">www.esrdnetworks.org/networks/net7/net7.htm</a>
8	<a href="http://www.esrdnetworks.org/networks/net8/net8.htm">www.esrdnetworks.org/networks/net8/net8.htm</a>
9/10	<a href="http://www.therenalnetwork.org">www.therenalnetwork.org</a>
11	<a href="http://www.esrdnetworks.org/networks/net11/net11.htm">www.esrdnetworks.org/networks/net11/net11.htm</a>
12	<a href="http://www.esrdnetworks.org/networks/net12/net12.htm">www.esrdnetworks.org/networks/net12/net12.htm</a>
13	<a href="http://www.esrdnetworks.org/networks/net13/net13.htm">www.esrdnetworks.org/networks/net13/net13.htm</a>
14	<a href="http://www.nephron.com/net14.html">www.nephron.com/net14.html</a>
15	<a href="http://www.esrdnetworks.org/networks/net15/net15.htm">www.esrdnetworks.org/networks/net15/net15.htm</a>
16	<a href="http://www.nwrenalnetwork.org">www.nwrenalnetwork.org</a>
17	<a href="http://www.network17.org">www.network17.org</a>
18	<a href="http://www.esrdnetworks.org/networks/net18/net18.htm">www.esrdnetworks.org/networks/net18/net18.htm</a>
SIMS	<a href="http://www.simsproject.com">www.simsproject.com</a>

**Table 18**  
**ORGANIZATION WEB ADDRESSES**

<b>AHQA</b>	<a href="http://www.ahqa.org">www.ahqa.org</a>	<b>Medicare</b>	<a href="http://www.medicare.gov">www.medicare.gov</a>
<b>AAKP</b>	<a href="http://www.aakp.org">www.aakp.org</a>	<b>NAHQ</b>	<a href="http://www.nahq.org">www.nahq.org</a>
<b>ANNA</b>	<a href="http://anna.inurse.com">anna.inurse.com</a>	<b>NKF</b>	<a href="http://www.kidney.org">www.kidney.org</a>
<b>CDC</b>	<a href="http://www.cdc.gov">www.cdc.gov</a>	<b>UNOS</b>	<a href="http://unos.org">unos.org</a>
<b>HCFA</b>	<a href="http://www.hcfa.gov">www.hcfa.gov</a>	<b>USRDS</b>	<a href="http://www.usrds.org">www.usrds.org</a>

A copy of a specific Network Annual Report can be obtained from the Network office. Network addresses and telephone numbers are listed on the inside front cover of this report.

# APPENDIX A

## 1999 ESRD INCIDENCE AND DIALYSIS PREVALENCE BY NETWORK

Network	Patients New to ESRD in 1999	Patients Dialyzing 12/31/99
1	3,453	9,856
2	6,291	19,799
3	4,350	11,958
4	4,976	12,850
5	5,576	16,779
6	6,779	23,493
7	5,490	14,960
8	4,742	15,212
9	6,960	17,931
10	4,283	11,436
11	5,935	16,124
12	3,782	10,167
13	3,908	11,357
14	6,647	20,825
15	3,933	10,843
16	2,491	6,574
17	4,288	12,775
18	6,641	19,123
<b>Total</b>	<b>90,525</b>	<b>262,062</b>

Source: Networks 1-18 Annual Reports, 1999

**APPENDIX B**  
**INCIDENCE OF DIALYSIS POPULATION BY AGE AND NETWORK**  
**DECEMBER 31, 1999**

<b>Network</b>	<b>0-19</b>	<b>20-29</b>	<b>30-39</b>	<b>40-49</b>	<b>50-59</b>	<b>60-69</b>	<b>70-79</b>	<b>≥80</b>	<b>Unk</b>	<b>Total</b>
<b>1</b>	37	65	177	325	521	716	1,035	577	0	3,453
<b>2</b>	70	151	407	710	1,105	1,446	1,549	853	0	6,291
<b>3</b>	34	99	248	444	784	1,012	1,090	638	1	4,350
<b>4</b>	84	114	309	537	770	1,117	1,415	630	0	4,976
<b>5</b>	68	85	349	649	973	1,189	1,408	573	282	5,576
<b>6</b>	59	242	480	888	1,351	1,624	1,500	623	12	6,779
<b>7</b>	62	118	337	570	812	1,208	1,501	880	2	5,490
<b>8</b>	61	153	320	576	890	1,148	1,121	473	0	4,742
<b>9</b>	117	189	430	756	1,140	1,551	1,914	863	0	6,960
<b>10</b>	56	117	267	493	737	914	1,122	577	0	4,283
<b>11</b>	98	188	420	695	966	1,228	1,590	750	0	5,935
<b>12</b>	54	105	222	447	606	864	1,030	454	0	3,782
<b>13</b>	62	125	271	477	766	850	950	407	0	3,908
<b>14</b>	99	226	515	882	1,362	1,610	1,409	531	13	6,647
<b>15</b>	59	132	214	453	714	899	1,024	438	0	3,933
<b>16</b>	39	77	153	314	418	543	668	279	0	2,491
<b>17</b>	62	116	254	508	780	968	1,086	512	2	4,288
<b>18</b>	87	172	404	703	1,123	1,533	1,730	889	0	6,641
<b>Total</b>	<b>1,208</b>	<b>2,474</b>	<b>5,777</b>	<b>10,427</b>	<b>15,818</b>	<b>20,420</b>	<b>23,142</b>	<b>10,947</b>	<b>312</b>	<b>90,525</b>
<b>% Total</b>	<b>1%</b>	<b>3%</b>	<b>6%</b>	<b>12%</b>	<b>17%</b>	<b>23%</b>	<b>26%</b>	<b>12%</b>	<b>0%</b>	<b>100%</b>

Source: Networks 1-18 Annual Reports, 1999

**APPENDIX C**  
**1999 ESRD PREVALENCE OF DIALYSIS PATIENTS BY RACE IN**  
**NETWORK RECEIVING TREATMENT**

<b>Network</b>	<b>Black</b>	<b>White</b>	<b>Asian/ Pacific Islander</b>	<b>Native American</b>	<b>Other</b>	<b>Unknown</b>	<b>Total</b>
<b>1</b>	1,881	7,517	156	25	193	84	9,856
<b>2</b>	7,900	9,623	757	127	1,392	N/A	19,799
<b>3</b>	3,761	5,434	225	28	2,510	N/A	11,958
<b>4</b>	4,519	7,979	65	23	251	13	12,850
<b>5</b>	9,830	5,999	243	0	707	0	16,779
<b>6</b>	15,675	6,790	113	139	675	101	23,493
<b>7</b>	5,877	8,621	211	36	198	17	14,960
<b>8</b>	9,563	5,471	66	60	38	14	15,212
<b>9</b>	6,211	11,270	64	61	219	106	17,931
<b>10</b>	4,855	5,931	182	33	371	64	11,436
<b>11</b>	5,275	9,981	235	507	125	1	16,124
<b>12</b>	2,949	6,888	111	107	112	0	10,167
<b>13</b>	6,226	4,511	75	446	99	0	11,357
<b>14</b>	6,566	7,424	296	74	6,309	156	20,825
<b>15</b>	1,008	7,588	266	1,625	326	30	10,843
<b>16</b>	615	5,151	463	288	56	1	6,574
<b>17</b>	2,269	6,561	3,741	117	87	0	12,775
<b>18</b>	3,647	12,772	2,249	119	336	0	19,123
<b>Total</b>	<b>98,627</b>	<b>135,511</b>	<b>9,518</b>	<b>3,612</b>	<b>14,004</b>	<b>587</b>	<b>262,062</b>
<b>%Total</b>	<b>38%</b>	<b>52%</b>	<b>4%</b>	<b>1%</b>	<b>5%</b>	<b>0%</b>	<b>100%</b>

Source: Networks 1-18 Annual Reports, 1999. Patient numbers are derived from those patients receiving treatment

**APPENDIX D**  
**1999 ESRD INCIDENCE OF PATIENTS BY RACE**  
**AND NETWORK**

<b>Network</b>	<b>Black</b>	<b>White</b>	<b>Asian/ Pacific Islander</b>	<b>Native American</b>	<b>Other</b>	<b>Unknown</b>	<b>Total</b>
<b>1</b>	435	2,828	51	6	64	69	3,453
<b>2</b>	2,006	3,623	224	25	413	N/A	6,291
<b>3</b>	1,073	2,118	70	3	1,086	N/A	4,350
<b>4</b>	1,160	3,612	42	9	136	17	4,976
<b>5</b>	2,490	2,593	60	0	433	0	5,576
<b>6</b>	3,048	2,212	26	24	991	478	6,779
<b>7</b>	1,598	3,716	65	12	87	12	5,490
<b>8</b>	2,397	2,290	16	13	18	8	4,742
<b>9</b>	1,659	5,130	24	17	130	0	6,960
<b>10</b>	1,428	2,655	55	10	135	0	4,283
<b>11</b>	1,381	4,276	70	158	49	1	5,935
<b>12</b>	742	2,956	37	31	16	0	3,782
<b>13</b>	1,657	2,035	27	150	39	0	3,908
<b>14</b>	1,689	3,015	94	26	1,808	15	6,647
<b>15</b>	285	3,013	83	384	159	9	3,933
<b>16</b>	151	2,065	138	107	29	1	2,491
<b>17</b>	574	2,501	1,124	33	55	1	4,288
<b>18</b>	998	4,741	722	36	144	0	6,641
<b>Total</b>	<b>24,771</b>	<b>55,379</b>	<b>2,928</b>	<b>1,044</b>	<b>5,792</b>	<b>611</b>	<b>90,525</b>
<b>%</b>	<b>27%</b>	<b>61%</b>	<b>3%</b>	<b>1%</b>	<b>6%</b>	<b>1%</b>	<b>100%</b>

Source: Networks 1-18 Annual Reports, 1999. Patient Numbers Are Derived From Those Patients Receiving Treatment.

**APPENDIX E**  
**LIST OF PRIMARY CAUSES OF END STAGE RENAL DISEASE**

**Diabetes**

- Type II, adult-onset
- Type I, juvenile type

**Glomerulonephritis**

- Glomerulonephritis (GN)
- Focal glomerulonephritis
- Membranous nephropathy
- Membranoproliferative GN
- Dense deposit disease
- IgA nephropathy, Berger's disease
- IgM nephropathy
- Rapidly progressive GN
- Goodpasture's Syndrome
- Post infectious GN
- Other proliferative GN

**Hypertension/Large Vessel Disease**

- Renal disease due to hypertension
- Renal artery stenosis
- Renal artery occlusion
- Cholesterol emboli, renal emboli

**Cystic/Hereditary/Congenital Diseases**

- Polycystic kidneys, adult type
- Polycystic, infantile
- Medullary cystic disease
- Tuberous sclerosis
- Hereditary nephritis, Alport's syndrome
- Cystinosis
- Primary oxalosis
- Fabry's disease
- Congenital nephrotic syndrome
- Drash syndrome
- Congenital obstructive uropathy
- Renal hypoplasia, dysplasia, oligonephronia
- Prune belly syndrome
- Hereditary/familial nephropathy

**Other**

**Secondary GN/Vasculitis**

- Lupus erythematosus
- Henoch-Schonlein syndrome
- Sclerodema
- Hemolytic uremic syndrome
- Polyarteritis
- Wegener's granulomatosis
- Nephropathy due to heroin abuse and related drugs
- Vasculitis and its derivatives
- Secondary GN, other

**Interstitial Nephritis/Pyelonephritis**

- Analgesic abuse
- Radiation nephritis
- Lead nephropathy
- Gouty nephropathy
- Nephrolithiasis
- Acquired obstructive uropathy
- Chronic pyelonephritis
- Chronic interstitial nephritis
- Acute interstitial nephritis
- Urolithiasis
- Nephrocalcinosis

**Neoplasms/Tumors**

- Renal tumor (malignant, benign, or unspecified)
- Urinary tract tumor (malignant, benign, or unspecified)
- Lymphoma of kidneys
- Multiple myeloma
- Light chain nephropathy
- Amyloidosis
- Complication post bone marrow or other transplant

**Miscellaneous Conditions**

- Sickle cell disease/anemia
- Sickle cell trait and other sickle cell
- Post partum renal failure
- AIDS nephropathy
- Traumatic or surgical loss of kidneys
- Hepatorenal syndrome
- Tubular necrosis
- Other renal disorders
- Etiology uncertain

Source: HCFA 2728 ESRD Medical Evidence Report Form

**APPENDIX F**  
**1999 ESRD INCIDENCE BY PRIMARY DIAGNOSIS**

<b>Network</b>	<b>Diabetes</b>	<b>Hypertension</b>	<b>GN</b>	<b>Cystic Kidney Disease</b>	<b>Other Causes</b>	<b>Unknown</b>	<b>Total</b>
<b>1</b>	1,368	844	393	135	655	58	3,453
<b>2</b>	2,562	1,306	593	142	1,195	493	6,291
<b>3</b>	2,047	1,006	473	106	587	131	4,350
<b>4</b>	2,001	1,216	531	141	973	114	4,976
<b>5</b>	2,241	1,681	697	153	804	0	5,576
<b>6</b>	2,359	1,563	478	135	824	1,420	6,779
<b>7</b>	2,154	1,708	446	198	984	0	5,490
<b>8</b>	2,065	1,549	348	146	591	43	4,742
<b>9</b>	3,101	1,464	816	178	1,362	39	6,960
<b>10</b>	1,735	1,176	440	81	812	39	4,283
<b>11</b>	2,493	1,546	529	172	999	196	5,935
<b>12</b>	1,602	1,024	368	153	510	125	3,782
<b>13</b>	1,771	1,244	343	102	315	133	3,908
<b>14</b>	3,362	1,482	687	196	856	64	6,647
<b>15</b>	1,797	683	357	134	957	5	3,933
<b>16</b>	1,089	454	349	138	320	141	2,491
<b>17</b>	1,947	929	583	149	680	0	4,288
<b>18</b>	3,171	1,891	581	183	815	0	6,641
<b>Total</b>	<b>38,865</b>	<b>22,766</b>	<b>9,012</b>	<b>2,642</b>	<b>14,239</b>	<b>3,001</b>	<b>90,525</b>
<b>% of Total</b>	<b>43%</b>	<b>25%</b>	<b>10%</b>	<b>3%</b>	<b>16%</b>	<b>3%</b>	<b>100%</b>

Source: Networks 1-18 Annual Reports, 1999



**APPENDIX G**  
**1999 INCIDENCE OF DIALYSIS PATIENTS BY NETWORK PROVIDING TREATMENT**

<b>Network</b>	<b>Male</b>	<b>Female</b>	<b>Unknown</b>	<b>Total</b>
<b>1</b>	1,897	1,556	0	3,453
<b>2</b>	3,445	2,846	0	6,291
<b>3</b>	2,404	1,946	0	4,350
<b>4</b>	2,712	2,264	0	4,976
<b>5</b>	2,798	2,545	233	5,576
<b>6</b>	2,672	2,725	1,382	6,779
<b>7</b>	3,111	2,378	1	5,490
<b>8</b>	2,396	2,346	0	4,742
<b>9</b>	3,746	3,211	3	6,960
<b>10</b>	2,342	1,940	1	4,283
<b>11</b>	3,188	2,747	0	5,935
<b>12</b>	1,985	1,797	0	3,782
<b>13</b>	1,938	1,970	0	3,908
<b>14</b>	3,405	3,242	0	6,647
<b>15</b>	2,238	1,689	6	3,933
<b>16</b>	1,400	1,091	0	2,491
<b>17</b>	2,330	1,956	2	4,288
<b>18</b>	3,562	3,079	0	6,641
<b>Total</b>	<b>47,569</b>	<b>41,328</b>	<b>1,628</b>	<b>90,525</b>
<b>% Total</b>	<b>53%</b>	<b>46%</b>	<b>2%</b>	<b>100%</b>

Source: Networks 1-18 Annual Reports, 1999

**APPENDIX H**  
**1999 PREVALENCE OF DIALYSIS PATIENTS BY GENDER BY NETWORK**  
**PROVIDING TREATMENT**

<b>Network</b>	<b>Male</b>	<b>Female</b>	<b>Unknown</b>	<b>Total</b>
<b>1</b>	5,347	4,509	0	9,856
<b>2</b>	10,781	9,018	0	19,799
<b>3</b>	6,743	5,215	0	11,958
<b>4</b>	6,916	5,934	0	12,850
<b>5</b>	8,718	7,810	251	16,779
<b>6</b>	11,618	11,868	7	23,493
<b>7</b>	8,236	6,723	1	14,960
<b>8</b>	7,578	7,634	0	15,212
<b>9</b>	9,456	8,460	15	17,931
<b>10</b>	6,107	5,326	3	11,436
<b>11</b>	8,673	7,451	0	16,124
<b>12</b>	5,278	4,889	0	10,167
<b>13</b>	5,753	5,604	0	11,357
<b>14</b>	10,494	10,331	0	20,825
<b>15</b>	5,782	5,059	2	10,843
<b>16</b>	3,605	2,969	0	6,574
<b>17</b>	6,677	6,093	5	12,775
<b>18</b>	10,055	9,068	0	19,123
<b>Total</b>	<b>137,817</b>	<b>123,961</b>	<b>284</b>	<b>262,062</b>
<b>% Total</b>	<b>53%</b>	<b>47%</b>	<b>0%</b>	<b>100%</b>

Source: Networks 1-18 Annual Reports, 1999

**APPENDIX I**  
**IN-CENTER DIALYSIS PATIENTS BY NETWORK AND MODALITY**  
**DECEMBER 31, 1999**

<b>NETWORK</b>	<b>Hemodialysis</b>	<b>Peritoneal Dialysis</b>	<b>Total</b>
<b>1</b>	8,515	35	8,550
<b>2</b>	17,527	16	17,543
<b>3</b>	10,489	7	10,496
<b>4</b>	11,653	4	11,657
<b>5</b>	14,600	2	14,602
<b>6</b>	21,032	2	21,034
<b>7</b>	13,512	9	13,521
<b>8</b>	13,529	9	13,538
<b>9</b>	15,531	29	15,560
<b>10</b>	10,164	18	10,182
<b>11</b>	14,088	0	14,088
<b>12</b>	8,527	0	8,527
<b>13</b>	10,318	11	10,329
<b>14</b>	19,175	8	19,183
<b>15</b>	9,668	13	9,681
<b>16</b>	5,523	7	5,530
<b>17</b>	11,219	4	11,223
<b>18</b>	17,264	12	17,276
<b>Total</b>	<b>232,334</b>	<b>186</b>	<b>232,520</b>

Source: Networks 1-18 Annual Reports, 1999

**APPENDIX J**  
**HOME DIALYSIS PATIENTS BY NETWORK**  
**DECEMBER 31, 1999**

<b>NETWORK</b>	<b>Hemodialysis</b>	<b>CAPD</b>	<b>CCPD</b>	<b>Other PD</b>	<b>Total</b>
<b>1</b>	50	520	688	0	1,258
<b>2</b>	87	861	758	6	1,712
<b>3</b>	46	534	850	0	1,430
<b>4</b>	33	416	674	3	1,126
<b>5</b>	127	895	731	4	1,757
<b>6</b>	168	1,275	1,192	15	2,650
<b>7</b>	191	521	734	0	1,446
<b>8</b>	115	682	740	6	1,543
<b>9</b>	65	1,390	908	8	2,371
<b>10</b>	100	684	467	3	1,254
<b>11</b>	70	1,223	742	1	2,036
<b>12</b>	131	854	657	0	1,642
<b>13</b>	34	546	448	0	1,028
<b>14</b>	66	698	1,000	4	1,768
<b>15</b>	70	525	586	0	1,181
<b>16</b>	199	513	359	3	1,074
<b>17</b>	24	628	845	0	1,497
<b>18</b>	22	967	941	0	1,930
<b>Total</b>	<b>1,598</b>	<b>13,732</b>	<b>13,320</b>	<b>53</b>	<b>28,703</b>

Source: Networks 1-18 Annual Reports, 1999

**APPENDIX K  
1998 AND 1999 DIALYSIS MODALITY: IN CENTER**

Network	HEMO			PD		
	1998	1999	% Change	1998	1999	% Change
1	8,138	8,515	5%	30	35	17%
2	16,214	17,527	8%	14	16	14%
3	9,626	10,489	9%	1	7	600%
4	11,099	11,653	5%	9	4	-56%
5	13,955	14,600	5%	45	2	-96%
6	19,786	21,032	6%	0	2	N/A
7	12,489	13,512	8%	2	9	350%
8	13,428	13,529	1%	5	9	80%
9	14,537	15,531	7%	30	29	-3%
10	9,614	10,164	6%	12	18	50%
11	13,369	14,088	5%	0	0	0%
12	7,821	8,527	9%	0	0	0%
13	9,638	10,318	7%	4	11	175%
14	17,634	19,175	9%	18	8	-56%
15	8,844	9,668	9%	2	13	550%
16	5,052	5,523	9%	13	7	-46%
17	10,389	11,219	8%	12	4	- 67%
18	16,027	17,264	8%	13	12	-8%
<b>Total</b>	<b>217,660</b>	<b>232,334</b>	<b>7%</b>	<b>210</b>	<b>186</b>	<b>-11%</b>

Source: Networks 1-18 Annual Reports, 1999

**APPENDIX L**  
**1998 and 1999 DIALYSIS MODALITY: SELF-CARE SETTING - HOME**

Network	HEMO			CAPD			CCPD			OTHER PD		
	1998	1999	% Change	1998	1999	% Change	1998	1999	% Change	1998	1999	% Change
<b>1</b>	50	50	0	583	520	-11%	693	688	-1%	1	0	-100%
<b>2</b>	145	87	-40%	1,038	861	-17%	781	758	-3%	0	6	N/A
<b>3</b>	55	46	-16%	655	534	-18%	826	850	3%	0	0	0
<b>4</b>	59	33	-44%	511	416	-19%	624	674	8%	0	3	N/A
<b>5</b>	148	127	-14%	860	895	4%	810	731	-10%	10	4	-60%
<b>6</b>	176	168	-5%	1,433	1,275	-11%	1,141	1,192	4%	18	15	-17%
<b>7</b>	162	191	-18%	508	521	3%	726	734	1%	0	0	0
<b>8</b>	193	115	-40%	1,004	682	-32%	741	740	-.1%	10	6	-40%
<b>9</b>	65	65	0	1606	1390	-13%	850	908	7%	11	8	-27%
<b>10</b>	65	100	-54%	704	684	-3%	408	467	14%	2	3	50%
<b>11</b>	76	70	-8%	1,336	1,223	-8%	724	742	2%	1	1	0
<b>12</b>	136	131	-4%	928	854	-8%	647	657	2%	0	0	0
<b>13</b>	22	34	-55%	607	546	-10%	420	448	7%	2	0	-100%
<b>14</b>	66	66	0	796	698	-12%	930	1000	8%	2	4	100%
<b>15</b>	62	70	-13%	578	525	-9%	565	586	4%	1	0	-100%
<b>16</b>	220	199	-10%	558	513	-8%	340	359	6%	15	3	-53%
<b>17</b>	25	24	-4%	685	628	-8%	746	845	13%	0	0	0
<b>18</b>	17	22	-29%	1,078	967	-10%	837	941	12%	1	0	-100%
<b>Total</b>	<b>1,742</b>	<b>1,598</b>	<b>-8%</b>	<b>15,468</b>	<b>13,732</b>	<b>-11%</b>	<b>12,809</b>	<b>13,320</b>	<b>4%</b>	<b>73</b>	<b>53</b>	<b>-27%</b>

Source: Networks 1-18 Annual Reports, 1999

**APPENDIX M**  
**NUMBER OF RENAL TRANSPLANTS PERFORMED**  
**CALENDAR YEAR 1999**

<b>NETWORK</b>	<b>Total Kidney Transplants</b>	<b>Patients Waiting for Kidney Transplants*</b>
<b>1</b>	605	2,135
<b>2</b>	871	4,293
<b>3</b>	389	1,945
<b>4</b>	902	2,858
<b>5</b>	1,106	3,529
<b>6</b>	782	2,414
<b>7</b>	663	1,389
<b>8</b>	660	1,888
<b>9</b>	842	2,047
<b>10</b>	406	1,891
<b>11</b>	1,423	3,725
<b>12</b>	679	1,345
<b>13</b>	414	1,393
<b>14</b>	990	2,092
<b>15</b>	635	1,653
<b>16</b>	466	989
<b>17</b>	594	4,358
<b>18</b>	973	3,977
<b>Total</b>	<b>13,400</b>	<b>43,921</b>

Source: Networks 1-18 Annual Reports, 1999, Table 5

\*\*Patients may be placed on more than one transplant center's waiting list, so patients may be counted more than once

*Note: This Appendix may vary from Table 5 and Appendix P which counts recipients by Network rather than transplants performed by center within Network.*

**APPENDIX N**  
**RENAL TRANSPLANT RECIPIENTS BY DONOR SOURCE**  
**CALENDAR YEAR 1999**

<b>NETWORK</b>	<b>Cadaver</b>	<b>Living Related</b>	<b>Living Unrelated</b>	<b>Unknown</b>	<b>Total</b>
<b>1</b>	330	200	75	0	605
<b>2</b>	548	256	67	0	871
<b>3</b>	226	99	47	17	389
<b>4</b>	776	157	23	11	967
<b>5</b>	518	273	21	90	902
<b>6</b>	528	212	42	0	782
<b>7</b>	560	132	36	0	728
<b>8</b>	418	211	30	1	660
<b>9</b>	688	226	0	4	918
<b>10</b>	387	137	0	3	527
<b>11</b>	801	463	158	0	1,422
<b>12</b>	438	169	72	0	679
<b>13</b>	288	111	15	0	414
<b>14</b>	735	221	34	0	990
<b>15</b>	382	183	64	7	636
<b>16</b>	273	147	46	0	466
<b>17</b>	407	146	41	0	594
<b>18</b>	674	256	43	0	973
<b>Total</b>	<b>8,977</b>	<b>3,599</b>	<b>814</b>	<b>133</b>	<b>13,523</b>

Source: Networks 1-18 Annual Reports, 1999, Table 6



**APPENDIX O**  
**VOCATIONAL REHABILITATION**  
**PATIENTS AGED 18-55 YEARS AS OF DECEMBER 31, 1999**

<b>NETWORK</b>	<b>Number of Patients Age 18-55</b>	<b>Referrals to Vocational Rehabilitation</b>	<b>Patients Employed or Attending School Full or Part time</b>	<b>Facilities Offering Dialysis Shift after 5 pm</b>
<b>1</b>	3,012	140	1,073	72
<b>2</b>	6,697	594	1,898	116
<b>3</b>	3,212	450	1,738	69
<b>4</b>	3,873	304	937	50
<b>5</b>	6,025	897	1,740	58
<b>6</b>	9,075	929	1,708	43
<b>7</b>	5,078	417	1,136	51
<b>8</b>	5,944	265	930	26
<b>9</b>	6,352	489	1,104	103
<b>10</b>	4,034	391	673	45
<b>11</b>	5,681	450	1,330	55
<b>12</b>	2,979	288	1,106	38
<b>13</b>	4,517	537	934	40
<b>14</b>	8,782	695	1,997	42
<b>15</b>	4,068	526	1,180	51
<b>16</b>	2,483	333	758	53
<b>17</b>	4,787	260	1,343	55
<b>18</b>	7,053	970	1,769	73
<b>Total</b>	<b>84,879</b>	<b>8,935</b>	<b>23,354</b>	<b>1,040</b>

Source: Networks 1-18 Annual Reports, 1999

**APPENDIX P**  
**LIST OF ACRONYMS**

<b>ACRONYM</b>	<b>EXPLANATION</b>
<b>BOD</b>	Board of Directors
<b>CAPD</b>	Continuous Ambulatory Peritoneal Dialysis
<b>CQI</b>	Continuous Quality Improvement
<b>DMMS</b>	Dialysis Mortality and Morbidity Study
<b>DOQI</b>	Dialysis Outcomes Quality Initiative
<b>EDEES</b>	ESRD Data Entry and Editing System
<b>ESRD</b>	End Stage Renal Disease
<b>HCFA</b>	Health Care Financing Administration
<b>HCQIP</b>	Health Care Quality Improvement Program
<b>HD</b>	Hemodialysis
<b>MRB</b>	Medical Review Board
<b>PRO</b>	Peer Review Organization
<b>QIP</b>	Quality Improvement Project
<b>SIMS</b>	Standard Information Management System
<b>SOW</b>	Statement of Work
<b>SSA</b>	State Survey Agency
<b>URR</b>	Urea Reduction Ratio
<b>USRDS</b>	United States Renal Data System