
1998 Annual Report Summary

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 1998.

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 7%-8% per year impacting all races, age groups and socioeconomic standings. Because the ESRD Network Organizations cover all 50 states plus Puerto Rico, Saipan 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 1998 there were 248,845 patients being dialyzed and 87,301 were newly diagnosed (Appendix A). As seen in Appendix B, Washington, DC had the highest incidence rate, 804.78 per million, while Alaska had the lowest at 109.12 per million. Of the U.S. territories, American Samoa has the lowest incidence rate with only 144.94 cases per million population. Although the incidence in some states has fallen slightly, the overall incidence and prevalence of ESRD continues to rise nationally. Appendix C displays the incidence data for 1997 and 1998 by Network. The national average incidence rate has risen to over 317 cases per million population and the overall ESRD prevalence counts have more than doubled since 1988 (USRDS 1999).

The Forum of ESRD Networks aggregated data obtained from the ESRD Networks to calculate both state and national incidence rates for 1998 (Table 1 and Appendix B). Included in the count were all new ESRD patients, both dialysis and transplant, as well as all non-Medicare patients reported to the Networks.

Incidence rates are calculated by dividing the number of new cases by the general population. The U.S. Bureau of Census estimated population for July 1, 1998 was used in the calculation.

Table 1
ESRD Incidence Rates by network
CALENDAR YEAR 1998

Network based Patients' Residence	Initiated ESRD Therapy	General Population	Incidence Rate Per Million Population
1	3,473	13,429,862	257.34
2	6,201	18,175,301	341.07
3	4,100	12,093,393	339.03
4	4,577	12,745,054	358.81
5	5,550	14,260,433	376.57
6	6,833	19,024,662	356.69
7	5,192	14,915,980	348.02
8	4,421	12,534,712	352.70
9	6,889	21,045,187	327.34
10	4,395	12,045,326	364.87
11	5,863	21,142,576	277.07
12	3,554	12,592,792	282.22
13	3,649	10,253,983	355.86
14	6,323	19,759,614	320.00
15	3,677	14,704,096	250.00
16	2,179	11,694,384	186.33
17/18*	10,425	34,137,356	305.30
Total	87,301	274,554,711	317.97

Source: Forum of ESRD Networks

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

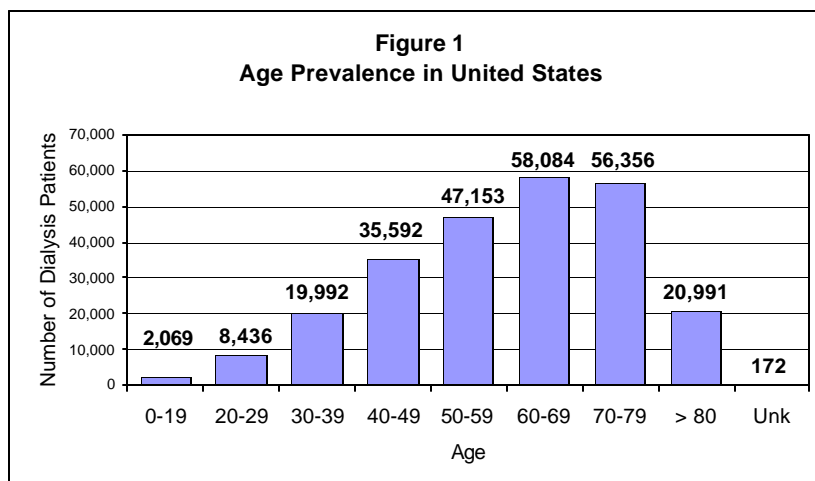
- **AGE**

In 1998 a majority of the ESRD patients were between the ages of 60 and 79 with the pediatric population remaining 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 D).

Table 2
Prevalence of Dialysis Population by Age and Network
December 31, 1998

Network	0-19	20-29	30-39	40-49	50-59	60-69	70-79	≥ 80	Unk	Total
1	50	266	688	1,086	1,528	2,142	2,637	1,209	0	9,606
2	163	595	1,516	2,761	3,685	4,294	4,104	1,711	0	18,829
3	93	349	886	1,556	2,292	2,768	2,531	919	0	11,394
4	96	324	843	1,590	2,087	2,934	3,287	1,224	0	12,385
5	145	481	1,309	2,442	3,082	3,690	3,471	1,109	136	15,865
6	136	790	1,975	3,481	4,838	5,431	4,395	1,403	1	22,450
7	96	437	1,061	1,903	2,480	3,269	3,491	1,531	0	14,268
8	108	551	1,210	2,272	2,907	3,479	2,952	956	0	14,435
9	157	572	1,429	2,405	3,019	4,076	4,237	1,443	13	17,351
10	117	341	844	1,550	1,951	2,504	2,684	997	3	10,991
11	93	507	1,107	2,088	2,726	3,297	4,000	1,683	0	15,501
12	93	320	744	1,294	1,643	2,149	2,307	983	0	9,533
13	79	418	914	1,720	2,147	2,615	2,083	723	0	10,699
14	189	729	1,632	3,057	4,028	4,793	3,888	1,155	3	19,474
15	102	339	874	1,373	2,013	2,414	2,251	687	3	10,056
16	75	258	546	901	1,139	1,352	1,385	542	0	6,198
17	72	366	896	1,661	2,281	2,723	2,715	1,175	13	11,902
18	205	793	1,518	2,452	3,307	4,154	3,938	1,541	0	17,908
Total	2,069	8,436	19,992	35,592	47,153	58,084	56,356	20,991	172	248,845
% Total	1%	3%	8%	14%	19%	23%	23%	8%	0	

Source: 1998 Network Annual Reports



Source: 1998 Network Annual Reports

- **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 and Native Americans establish less than 1% of the US population and 2% of the ESRD population. Network 6 has a large population of Blacks and Network 15 is home to a large number of Native Americans. Appendices E and F present tables comparing the prevalent and incident ESRD population 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 G.

Table 3
Prevalence of Dialysis Population by Primary Diagnosis and Network
December 31, 1998

Network	Diabetes	Hypertension	GN	Cystic Kidney	Other¹	Unknown²	Total
1	3,452	2,335	1,577	471	1,760	11	9,606
2	6,622	4,531	2,862	636	2,476	1,702	18,829
3	4,601	2,921	1,902	524	1,292	154	11,394
4	4,632	3,392	1,745	419	2,187	10	12,385
5	5,731	5,193	2,449	685	1,140	667	15,865
6	8,139	7,346	2,403	694	2,706	1,162	22,450
7	5,005	4,644	1,882	656	1,614	467	14,268
8	5,239	5,120	1,751	571	1,754	0	14,435
9	7,052	4,124	2,757	577	2,824	17	17,351
10	3,787	3,601	1,414	297	1,800	92	10,991
11	6,071	4,151	1,873	485	2,354	567	15,501
12	3,723	2,604	622	554	1,680	350	9,533
13	4,262	3,730	1,364	409	669	265	10,699
14	9,136	4,744	2,477	677	2,397	43	19,474
15	5,009	1,669	1,413	511	1,044	410	10,056
16	2,433	1,065	1,182	496	741	281	6,198
17	5,017	2,621	2,342	562	1,347	13	11,902
18	7,458	4,948	2,616	477	2,409	0	17,908
Total	97,369	68,739	34,631	9,701	32,194	6,211	248,845
%	39.1%	27.6%	13.9%	3.9%	12.9%	2.5%	

Source: 1998 Network Annual Reports

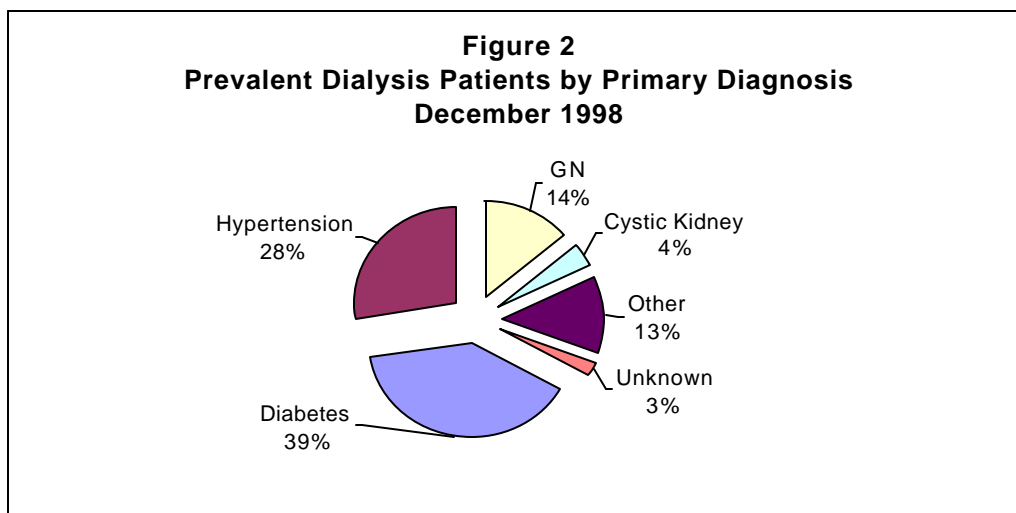
¹Other refers to those primary causes listed in Appendix G

²Unknown refers to causes both unknown and unreported

As shown by Figure 2, diabetes represented 39% of the prevalent dialysis patient population in 1998. Hypertension followed with 28%, glomerulonephritis with 14% and other causes accounted for 13% of the dialysis population with 3% of patients having an unknown primary cause. The percentage of patients with a primary diagnosis of diabetes is up slightly by 1% since 1997. With similar results, Appendix H 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 1998 but Network 15, at 50%, had the highest percentage of patients with this primary diagnosis. Network 8 joined the Networks in this category in 1998 by reporting a lower percent of their total patients with a primary diagnosis of hypertension.



- **GENDER**

In 1998, males represented over half of the ESRD incident and prevalent population, 53% and 52% respectively. With the exception of Networks 6 and 8, all Networks reported a higher ratio of males to females (Appendices I and J).

- **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 K and L display the number of 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 M). Continuous cycling peritoneal dialysis rose between 1997 and 1998 in most Networks. In-center peritoneal dialysis fell in all Networks as did CAPD (Appendix N).

TABLE 4
MEDICARE ESRD PROVIDERS BY TYPE OF SERVICE AND NETWORK
DECEMBER 31, 1998

Network	Total	Transplant	Dialysis	Hospital¹	Independent¹
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
Total	3,586	235	3,455	734	2,721

Source: National Listing of Medicare Providers Furnishing Kidney Dialysis and Transplant Services, January 1999

¹ 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, 13,212 transplants were performed at 235 transplant facilities within the United States during 1998. Of these transplants, 8,859 were from cadaveric donors while 3,498 were from living related donors and 825 from living non-related donors. Cadaveric donors represent 67% 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 1998 represented 33% of all transplants performed. The number of patients waiting for a kidney transplant is listed in Appendix O.

Table 5 and Appendix P 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 1998, 1,375. Network 3 performed the least number of transplants, 314 and had the least number of transplants by living related donor.

TABLE 5
KIDNEY TRANSPLANTS BY NETWORK
CALENDAR YEAR 1998

Network	Total Transplants	Cadaveric Donor	Living Related Donor	Living Unrelated Donor	Unknown
1	628	339	221	68	0
2	841	549	242	50	0
3	314	214	87	13	0
4	832	671	141	19	1
5	853	467	249	137	0
6	788	573	188	27	0
7	663	536	108	19	0
8	671	454	175	42	0
9	972	731	241	0	0
10	557	350	207	0	0
11	1,375	818	420	137	0
12	657	461	157	39	0
13	393	275	98	20	0
14	954	681	228	45	0
15	629	368	188	44	29
16	445	278	134	33	0
17	662	444	167	51	0
18	978	650	247	81	0
Total	13,212	8,859	3,498	825	30

Source: 1998 Facility Survey, Medicare Providers

NETWORK DESCRIPTION

The start of 1997 marked the 20th year of the ESRD Network program. 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 Scope of Work (SOW) in July 1997. The contract established a new 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 more significant to the daily operations of the Networks. As specified in the Scope 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, 1998

Network	Administrative		Quality		Data		Patient Services		Total Staff
	#	%	#	%	#	%	#	%	
1	3	33%	2	22%	3	33%	1	11%	9
2	3	30%	2	20%	4	40%	1	10%	10
3	4	36%	2	18%	5	46%	0	0%	11
4	3	37%	2	25%	3	37%	0	0	8
5	4	37%	3	27%	4	27%	1	9%	12
6	3	27%	3	27%	5	46%	0	0%	11
7	2	22%	2	22%	4	44%	1	11%	9
8	2	25%	2	25%	3	37%	1	13%	8
9/10	5	39%	2	15%	4	31%	2	15%	13
11	2	18%	3	27%	4	37%	1	9%	11
12	3	43%	2	29%	2	29%	0	0%	7
13	2	22%	2	22%	4	45%	1	11%	9
14	3	27%	4	37%	3	27%	1	9%	11
15	2	25%	2.5	31%	2.5	31%	1	12%	8
16	2	29%	1.5	21%	3.5	50%	0	0%	7
17	3	30%	3	30%	3	30%	1	%	10
18	3	37%	1	13%	4	44%	1	13%	9

Source: 1998 Network Annual Reports

As seen in Table 6, Networks operate with a relatively small number of employees for the size of the ESRD patient population served. The patterns of staffing are similar across the Networks, with respect to the number of staff assigned to functional categories but still reflect regional variations. Over seventy 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 Scope 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 their activities to meet and exceed HCFA expectations.

The four goals for 1998 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

■ QUALITY IMPROVEMENT PROJECTS

The Networks are required to conduct Quality Improvement Projects (QIPs) to assess and improve the outcomes of care provided to ESRD beneficiaries. Quality improvement, as defined in the Scope of Work is “a continuous process, using information from data on processes and outcomes of care to recognize opportunities to improve care and to develop measurable improvement initiatives.” A QIP is a collaborative effort between Networks and health care providers and/or beneficiaries, which results in a measurable improvement of outcomes. The Dialysis Outcome Quality Initiative (DOQI) clinical practice guidelines published in the fall of 1997 provide the foundation for Network QIPs. Each QIP submitted to HCFA for approval must fit into one of four broad categories. These are adequacy of dialysis, anemia, prevention, and vascular access. Table 7 and Appendix Q show the types of Quality Improvement Projects implemented by each Network during 1998.

**TABLE 7
QUALITY IMPROVEMENT PROJECTS
CALENDAR YEAR 1998**

Network	Title
1	Increasing the Utilization of Permanent Access in Incident Hemodialysis Patients Improving Influenza Vaccination Rates
2	Improving Peritoneal Dialysis Adequacy Measures Early Detection of Venous Stenosis in AVG's to Prevent Thrombosis
3	Vascular Access Cooperative Anemia
4	Adequacy of Dialysis Early Referral to Nephrology Care
5	Improving the Adequacy of Hemodialysis Dialysis in ESRD Network 5 Improving Influenza Vaccination Rates
6	Improving Influenza Vaccination Rates Improving Hepatitis B Vaccination Rates Peritoneal Adequacy
7	ESRD Hepatitis B Vaccine Study Cooperative ESRD Vascular Access
8	Hemodialysis Adequacy Improving Peritoneal Dialysis Adequacy in Network 8
9/10	Peritoneal Dialysis Prescription Adequacy Hemodialysis Central Venous Catheter
11	A Systems Based Approach to Quality Improvement Strategies for Managing the Continuum of Care in the ESRD Patient
12	Vascular Access Quality Improvement Project Improving Hepatitis B Vaccination Rates
13	Early Detection of Venous Stenosis in AVG's to Prevent Thrombosis Adequacy of Hemodialysis
14	ESRD Immunization Cooperative Project
15	Peritoneal Dialysis Adequacy Improving Influenza Vaccination Rates
16	Reducing the Rate of Hemodialysis Access Infection
17	Improving Adequacy of Hemodialysis Patients in Northern California ESRD Patients
18	Vascular Access: Increasing & Maintaining AV Fistulae Improving Hepatitis B Vaccination Rates

Source: 1998 Network Annual Reports

In addition to their QIPs, Networks promote improved quality through:

- Participating in the collection of Dialysis Outcomes Data (Core Indicators Project);
- Conducting special projects and studies;
- Encouraging patient vocational rehabilitation programs;
- Providing educational opportunities and materials;
- Collaborating with Peer Review Organizations on state specific quality initiatives; and
- Providing technical assistance to state survey agencies.

■ CORE INDICATORS PROJECT

The ESRD Core Indicators Project is a product of the joint efforts between HCFA, the Forum of ESRD Networks, Networks, and other members of the renal community. Implemented in July 1994, the project collects data on measurable treatment outcomes to generate national and Network-specific data that reflects care provided to ESRD patients. The purposes of the core indicators project are to:

- Assist ESRD providers in improving care delivered to dialysis patients;
- Compare the prevalence of important clinical characteristics for adult patients; and
- Identify opportunities to improve care.

The four areas of care monitored by the core indicators are:

- Adequacy of dialysis measured by urea reduction ratio (URR);
- Anemia management measured by hematocrit;
- Hypertension measured by pre/post dialysis diastolic and systolic blood pressure; and
- Nutritional status measured by serum albumin.

Annually, each Network validates the dialysis patient population within its geographic area. After the process is complete, a census report is produced for HCFA containing such items as name, gender, etiology of ESRD, Social Security Number, and date dialysis was initiated for every hemodialysis and peritoneal dialysis patient alive within the calendar year. HCFA then selects a random sample of in-center hemodialysis and peritoneal patients. In 1998, the sample consisted of 8,838 in-center hemodialysis patients and 1,650 peritoneal dialysis patients (Tables 8 & 9). Once a random sample of patients is chosen, HCFA then uses data specific collection forms to obtain core indicators data. Networks collect and enter each patient form into a standardized data file ensuring the data are correct. Once all the data are collected, HCFA analyzes the core indicators data and provides feedback reports to the Networks which, in turn, are distributed to dialysis providers.

Tables 8 and 9 illustrate the sample number of in-center hemodialysis and peritoneal patients within each Network that was taken at the end of 1998. As noted the sample ranges from 2.5% to 9.4% for hemodialysis patients.

TABLE 8
1998 CORE INDICATORS PROJECT
NUMBER OF ADULT (≥ 18 YEARS) IN-CENTER HEMODIALYSIS PATIENTS BY NETWORK AND SAMPLE SIZE
DECEMBER 1998

Network	Number of Hemodialysis Patients December 1998	Sample Size
1	8,181	485
2	16,701	497
3	9,509	489
4	11,170	492
5	13,982	494
6	19,544	498
7	12,333	493
8	14,163	495
9	13,958	494
10	9,275	488
11	12,949	494
12	7,788	485
13	9,594	489
14	17,745	498
15	8,788	488
16	5,033	472
17	10,386	490
18	15,945	497
Total	217,044	8,838

Source: 1999 ESRD Core Indicators Report

TABLE 9
1998 CORE INDICATORS PROJECT
NUMBER OF ADULT (= 18 YEARS) PERITONEAL DIALYSIS PATIENTS BY NETWORK
SAMPLE DECEMBER 1998

Network	Sample Size	Network	Sample Size
1	74	11	115
2	99	12	88
3	77	13	75
4	70	14	98
5	88	15	70
6	163	16	76
7	71	17	70
8	102	18	117
9	126		
10	71		
		Total	1,650

Source: 1999 ESRD Core Indicators Project

Figure 3
Percent of adult (aged ≥ 18 yrs) in-center hemodialysis patients with mean Kt/V ≥ 1.2 , by Network, in Oct-Dec 1998, 1999 ESRD Clinical Performance Measures Project

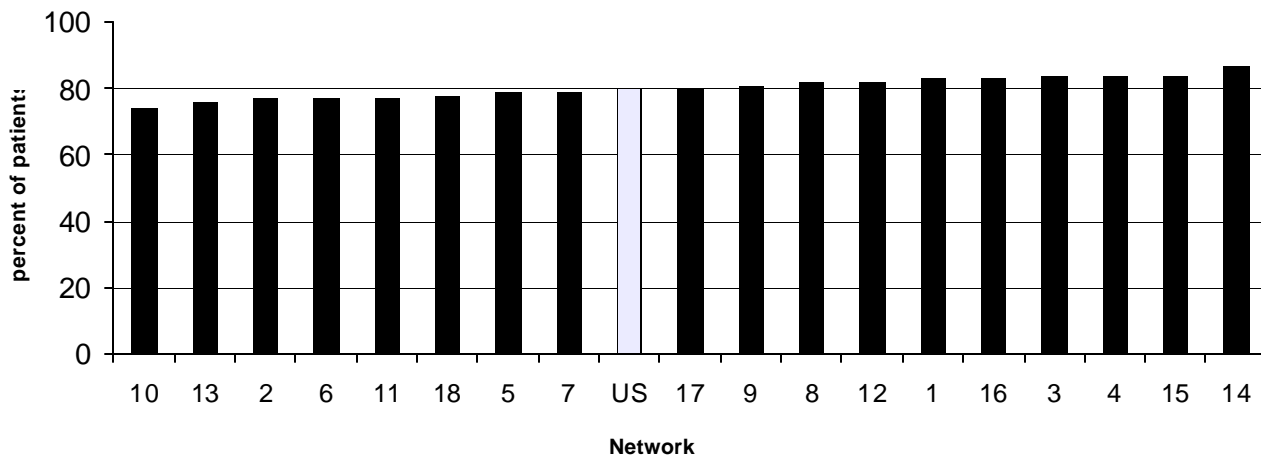
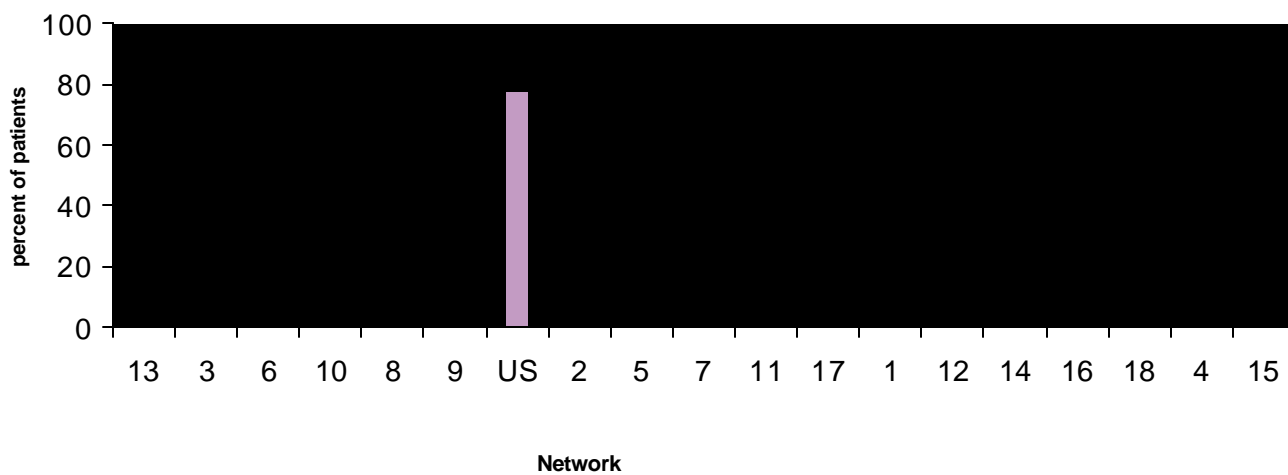


Figure 4
Percent of adult (aged ≥ 18 yrs) in-center hemodialysis patients with mean hemoglobin > 10 gm/dL, by Network, in Oct-Dec 1998, 1999 ESRD Clinical Performance Measures Project



The above figures (Figures 3 & 4) report findings for two of the core indicators, adequacy of dialysis and anemia, for the adult, in-center hemodialysis patients. These data are representative of the patients included in the 1998 core indicators sample. Using data collected on each selected patient, average values for adequacy of dialysis was calculated by Kt/V (a specific calculation factoring in patient size, time of treatment and dialyzer clearance). The percent of patients receiving adequate hemodialysis is displayed in ascending order by Network and for the U.S. Figure 3 shows the percentage of patients with a Kt/V \geq 1.2. The threshold used in reporting, Kt/V \geq 1.2, is the minimum acceptable level set forth by the DOQI Clinical Practice Guidelines. Figure 4 illustrates the percentage of patients with hemoglobin $>$ 10 gm/dL varied among the Networks, ranging from 72% to 85%.

Each year that the Core Indicators Project has been performed, there have been statistically and clinically significant improvements made in hemodialysis adequacy and anemia management. See ESRD Core Indicators Reports for more details.

■ SPECIAL STUDIES AND PROJECTS

Networks develop special studies to examine issues specific to each Network area and patient population. While these studies are often limited to only one Network area, some projects are developed to incorporate multiple Networks.

Examples of Network special studies are provided below as well as Appendix R:

- Network of New England Clinical Indicator Project (Network 1)
- Network Core Indicators Monitoring (Network 2)
- ESRD Emergency Preparedness Resources for Pennsylvania and Delaware Dialysis Facilities (Network 4)
- Vancomycin Resistant Enterococcus (VRE) (Network 5)
- Familial Clustering of End-Stage Renal Disease in HIV-Associated Nephropathy (Network 6)
- Evening Dialysis Study (Network 7)
- The Physician Activity Report (Network 9/10)
- Transplant Reviews (Network 11)
- Pre-ESRD (Network 15)
- Northwest Renal Mortality Report (Network 16)
- 1998 Pacific Island Core Indicators Follow-Up (Network 17)
- Heparinization Practice Project (Network 18)
- Cooperative National Study of Renal Decisions (CONSORD) (Networks 5, 8, 11, 18)

■ VOCATIONAL REHABILITATION

Networks are responsible for assisting providers in defining or establishing rehabilitation goals for referring suitable candidates to vocational rehabilitation programs. Networks study the patterns of patient employment within the Network area. They maintain and distribute vocational rehabilitation information to providers and patients. The vocational rehabilitation information includes dialysis shifts available after 5 pm, job placement programs, exercise programs, and educational materials.

Networks are contracted to report the number of patients between 18 and 55 years who are referred for vocational rehabilitation and the number of patients in this age category who are employed or attending school (full or part time). Table 10 provides the percentage of patients between 18 and 55 years in these two categories by Network. In calendar year 1998, Network 5 reported the highest percent of

referrals (16.5%) and Network 3 reported the highest percent of patients employed or attending school (40.1%). Appendix S provides additional information on vocational rehabilitation in the Networks.

TABLE 10
VOCATIONAL REHABILITATION BY NETWORK
DECEMBER 31, 1998

Network	% Patients 18-55 Years Referred to Vocational Rehabilitation	Percent of Patients 18-55 Years Employed or Attending School
1	4.0	31.2
2	7.7	29.6
3	11.1	40.1
4	6.5	26.7
5	16.5	27.0
6	10.4	19.7
7	7.4	21.2
8	2.6	19.2
9	3.0	25.5
10	6.3	19.9
11	10.0	26.1
12	7.5	36.0
13	13.8	20.1
14	7.5	23.2
15	12.3	34.5
16	16.1	31.1
17	7.8	24.4
18	8.2	23.9
National Average	8.81	26.6

Source: 1998 Network Annual Reports

■ EDUCATIONAL OPPORTUNITIES

Networks serve as a clearinghouse for educational materials with the purpose of increasing the understanding of End Stage Renal Disease, the care/treatment required, and other related issues. Networks distribute these materials not only to patients and their families, but also to other concerned parties such as dialysis facilities and other renal related organizations. An example of educational materials developed by some Networks include disaster preparedness guides; patient advocacy documents that help patients play a proactive role in improving their health; patient and facility newsletters; information on resolving patient grievances; and vocational rehabilitation information.

Networks also plan and provide support for various educational conferences throughout the year. These conferences benefit both the care providers as well as the patient population. Many Networks provide annual educational conferences and seminars directed toward nephrology nurses and technicians, nephrologists, and social workers. Often the seminars are held in conjunction with the American Nephrology Nurses Association and National Kidney Foundation.

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.

Each Network supports and maintains 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 ESRD Data Entry and Editing System (EDEES). Each month, Networks must upload all information collected in EDEES to the HCFA database. Table 11 shows the number of forms collected by Networks in 1998.

**TABLE 11
DATA FORMS PROCESSED
CALENDAR YEAR 1998**

Network	Medical Evidence (HCFA 2728)	Death Notification (HCFA 2746)	Total
1	3,690	2,530	6,220
2	6,414	4,240	10,654
3	3,050	2,924	5,974
4	4,583	2,937	7,520
5	5,705	3,659	9,364
6	6,910	4,333	11,243
7	*	*	9,548
8	4,760	3,294	8,054
9	6,699	4,267	10,966
10	3,871	2,327	6,198
11	6,000	4,000	10,000
12	3,912	2,602	6,514
13	3,986	2,660	9,548
14	6,327	4,038	10,365
15	3,878	2,263	6,141
16	2,265	1,477	3,742
17	4,093	2,661	6,754
18	6,707	4,216	10,923

Source: 1998 Network Annual Reports.
*Network numbers not provided

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 will also provide 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 with Beta testing expected to begin in June 1999. SIMS has an expected release date of December 1999 (Southeastern Kidney Council 1998 Annual Report).

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 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 Board of Directors as well as on various Forum committees.

The Forum, 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 received several contract modifications from HCFA in 1998 to assist in serving the Networks more efficiently. The Forum sponsored a 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 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.

In addition to working with the Forum, Networks foster relationships with Peer Review Organizations (PROs). As seen below in Table 12, Networks implemented cooperative studies in conjunction with the PROs in the area of quality improvement during 1998. The projects varied from Network to Network but all projects focused on improving the care received by ESRD patients.

TABLE 12
1998 NETWORK-PRO COLLABORATION PROJECTS

NETWORK	PRO	Topic or Project Name
2	Island Peer Review Organization	Monitoring AV Grafts for Early Detection of Venous Stenosis
5	Delmarva Foundation for Medical Care	Improving the adequacy of hemodialysis
5	West Virginia Medical Institute, Delmarva Foundation for Medical Care, Virginia Health Quality Center	Increasing the influenza vaccination rate
7	Florida Medical Quality Assurance, Inc.	Hepatitis B vaccination
8	Mid-South Foundation for Medical Care	Foot care
11	Michigan PRO North Dakota PRO	Flu vaccination Strategies for Managing the Continuum of Care in the ESRD Patient
13	Louisiana Health Care Review, Inc.	Vascular Access
14	Texas Medical Foundation	Be-Wise Immunize QIP protocol
15	Colorado Foundation for Medical Care	Peritoneal dialysis adequacy
15	Mountain Pacific Quality Health Foundation	Pre-ESRD Care
16	PRO-West	Vascular Access CPMs
17	CMRI, Inc	Hepatitis B vaccination and Immune status among ESRD patients in Northern California

Networks communicate with State Survey Agencies (SSAs) through the exchange of newsletters, annual reports, and other appropriate quality reports. The high degree of 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 work with include:

- **AAKP:** American Association of Kidney Patients
- **AKF:** American Kidney Fund
- **ANNA:** American Nephrology Nurses Association
- **ASN:** American Society of Nephrology
- **NKF:** National Kidney Foundation
- **NRAA:** National Renal Administrators Association
- **RPA:** Renal Physicians Association

Other organizations Networks work with include:

- **CDC:** Centers for Disease Control
- **FDA:** Food and Drug Administration
- **NAHQ:** National Association for Healthcare Quality
- **UNOS:** United Network for Organ Sharing
- **USRDS:** United States Renal Data System

Many of the ESRD Network personnel are actively involved on renal community Boards of Directors and committees. For example, several ESRD Network staff work closely with both the National Kidney Foundation (NKF) and the American Association of Kidney Patients (AAKP) to avoid duplication of services to patients within their Network area.

All ESRD Networks collaborate with UNOS to collect transplant data. The Networks' assist UNOS in collecting forms dealing with transplantation which are overdue and UNOS in turn supplies data and reports.

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. During 1998, Networks processed 105 formal beneficiary grievances. This represents a small decrease from 1997.

A formal beneficiary grievance is a documented complaint usually alleging that ESRD services did not meet professional levels of care. This type of 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.

Grievances come to the Networks 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.

Tables 13 displays the number and type of formal written grievances filed in each Network during 1998.

**TABLE 13
FORMAL GRIEVANCES PROCESSED
CALENDAR YEAR 1998**

Network	# of Grievances	Network	# of Grievances
1	0	11	0
2	12	12	5
3	0	13	8
4	1	14	10
5	10	15	3
6	22	16	0
7	10	17	2
8	16	18	1
9/10	18	Total	118

Source: 1998 Network Annual Reports

As noted, several Networks (1, 3, 11 and 16) had no formal grievance investigations in 1998 while Network 6 processed 22 formal grievances. Table 14 groups grievances into broad categories based on their general type given their description in each Network’s Annual Report. 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 14 TYPE OF GRIEVANCE
<p>Treatment Related</p> <ul style="list-style-type: none"> 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.
<p>Physical Environment</p> <ul style="list-style-type: none"> Any concern relating to the physical atmosphere of the unit. These may include temperature, cleanliness, hazards, etc.
<p>Staff/Provider Related</p> <ul style="list-style-type: none"> Any concern including difficulties with provider policies or staff such as professional behavior, competency, adherence to policy, etc.
<p>Disruptive/Abusive Patient</p> <ul style="list-style-type: none"> These complaints, lodged by the facility, concern how to handle a patient and/or family that is disruptive, abusive, or non-compliant.
<p>Patient Transfer Related</p> <ul style="list-style-type: none"> These complaints relate to the inter-facility patient transfer process.
<p>Transient Dialysis Related</p> <ul style="list-style-type: none"> Any complaint concerned with the facility assisting the patient and/or family in identifying a provider for temporary dialysis treatment.

Source: 1998 Network Annual Reports

■ SANCTION RECOMMENDATIONS

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

During 1998, only one sanction recommendation was made to HCFA. This sanction involved a facility that the Network felt its practices over time did not meet the standard of care and observed that the standardized mortality rate was consistently higher than the state average. The facility was not closed but was required to follow specific guidelines to monitor and improve deficiencies.

■ RECOMMENDATIONS FOR ADDITIONAL FACILITIES

There were three Networks recommending additional facilities in their area. These recommendations vary in their objectives which include:

- The need for a Medicare assessment of the costs to operate dialysis centers to include wage adjustments and local 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 in one Network.
- 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.

■ SUMMARY

This report summarizes highlights of ESRD Network's 1998 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 home page, www.esrdnetworks.org.

NETWORK WEB ADDRESSES

Network	
1	http://www.networkofnewengland.org
2	http://www.esrdnetworks.org/networks/net2/net2.htm
3	http://www.tarcweb.org
4	http://www.esrdnetworks.org/networks/net4/net4.htm
5	http://www.esrdnet5.org
6	http://www.esrdnetworks.org/networks/net6/net6.htm
7	http://www.esrdnetworks.org/networks/net7/net7.htm
8	http://www.esrdnetworks.org/networks/net8/net8.htm
9/10	http://www.renalnetwork.org
11	http://www.esrdnetworks.org/networks/net11/net11.htm
12	http://www.esrdnetworks.org/networks/net12/net12.htm
13	http://www.esrdnetworks.org/networks/net12/net12.htm
14	http://www.nephron.com/net14.html
15	http://www.esrdnetworks.org/networks/net15/net15.htm
16	http://www.nwrenalnetwork.org
17	http://www.network17.org
18	http://www.esrdnetworks.org/networks/net18/net18.htm
SIMS Project	http://www.simsproject.com

ORGANIZATION WEB ADDRESSES

AHQA	http://www.ahqa.org
AAKP	http://www.aakp.org
ANNA	http://anna.inurse.com
CDC	http://www.cdc.gov
HCFA	http://www.hcfa.gov

Medicare	http://www.medicare.gov
NAHQ	http://www.nahq.org
NKF	http://www.kidney.org
UNOS	http://www.unos.org
USRDS	http://www.usrds.org

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
1998 INCIDENCE AND PREVALENCE BY DIALYZING NETWORK

Network	Patients New to ESRD in 1998	Patients Dialyzing at 12/31/1998
1	3,469	9,606
2	6,196	18,829
3	3,980	11,394
4	4,698	12,385
5	5,588	15,865
6	6,809	22,450
7	5,182	14,268
8	4,464	14,435
9	6,937	17,351
10	4,215	10,991
11	5,882	15,501
12	3,608	9,533
13	3,622	10,699
14	6,388	19,474
15	3,679	10,056
16	2,184	6,198
17	4,112	11,902
18	6,288	17,908
Total	87,301	248,845

Source: 1998 Network Annual Reports

APPENDIX B
STATE AND NATIONAL ESRD INCIDENCE RATES
CALENDAR YEAR 1998

Patients' Residence	Initiated ESRD Therapy 1998	General Population (7/1/98)	Incidence Rate Per Million Population
Alabama	1,564	4,351,999	359.38
Alaska	67	614,010	109.12
Arizona	1,580	4,668,631	338.43
Arkansas	734	2,538,303	289.17
California	9,861	32,666,550	301.87
Colorado	761	3,970,971	191.64
Connecticut	948	3,274,096	289.55
Delaware	252	743,603	338.89
District of Columbia	421	523,124	804.78
Florida	5,191	14,915,980	348.02
Georgia	2,567	7,642,207	335.90
Hawaii	457	1,193,001	383.07
Idaho	230	1,228,684	187.19
Illinois	4,395	12,045,326	364.87
Indiana	1,864	5,899,195	315.98
Iowa	666	2,862,447	232.67
Kansas	656	2,629,067	249.52
Kentucky	1,160	3,936,499	294.68
Louisiana	1,928	4,368,967	441.29
Maine	247	1,244,250	198.51
Maryland	2,018	5,134,808	393.00
Massachusetts	1,625	6,147,132	264.35
Michigan	3,131	9,817,242	318.93
Minnesota	1,058	4,725,419	223.90
Mississippi	1,105	2,752,092	401.51
Missouri	1,799	5,438,559	330.79
Montana	158	880,453	179.45
Nebraska	433	1,662,719	260.42
Nevada	459	1,746,898	262.75
New Hampshire	219	1,185,048	184.80
New Jersey	3,003	8,115,011	370.05
New Mexico	466	1,736,931	268.29
New York	6199	18,175,301	341.07
North Carolina	2,712	7,546,439	359.37
North Dakota	127	638,244	198.98
Ohio	3,865	11,209,493	344.80
Oklahoma	987	3,346,713	294.92
Oregon	649	3,281,974	197.75
Pennsylvania	4,321	12,001,451	360.04
Rhode Island	301	988,480	304.51
South Carolina	1,507	3,835,962	392.86
South Dakota	199	738,171	269.59
Tennessee	1,752	5,430,621	322.62
Texas	6,323	19,759,614	320.00
Utah	336	2,099,758	160.02
Vermont	116	590,883	196.32
Virginia	2,319	6,791,345	341.46
Washington	1,075	5,689,263	188.95
West Virginia	612	1,811,156	337.91
Wisconsin	1,343	5,223,500	257.11
Wyoming	74	480,907	153.88

APPENDIX B
STATE AND NATIONAL ESRD INCIDENCE RATES
CALENDAR YEAR 1998

Patients' Residence	Initiated ESRD Therapy 1998	General Population (7/1/98)	Incidence Rate Per Million Population
Unknown US	239		
United States	86,079	270,298,524	318.46
American Samoa	9	62,093	144.94
Guam	73	149,101	489.60
Puerto Rico	1,062	3,860,000	275.13
Saipan	22	66,611	330.28
Virgin Islands	35	118,382	295.65
Unknown	7		
US and Territories	87,287	274,554,711	317.92
Outside US	14		
Total New ESRD	87,301	274,554,711	317.97

Source of Population Census: <http://www.census.gov/population/estimates/state/ST9097T1.txt>
<http://www.census.gov/cgi-bin/ipc/idbsprd>

APPENDIX C
INCIDENCE INCREASE (DECREASE) FROM END YEAR 1997 AND
End Year 1998

Patients' Residence	Initiated ESRD Therapy 1997	Initiated ESRD Therapy 1998	% Difference
Alabama	1,649	1,564	-5%
Alaska	75	67	-11%
Arizona	1,378	1,580	15%
Arkansas	788	734	-7%
California	9,094	9,861	8%
Colorado	683	761	11%
Connecticut	946	948	0.00
Delaware	184	252	37%
District of Columbia	378	421	11%
Florida	4,955	5,191	5%
Georgia	2,433	2,567	6%
Hawaii	420	457	9%
Idaho	214	230	7%
Illinois	3,998	4,395	10%
Indiana	1,618	1,864	15%
Iowa	595	666	12%
Kansas	670	656	-2%
Kentucky	1,066	1,160	9%
Louisiana	1,722	1,928	12%
Maine	257	247	-4%
Maryland	1,810	2,018	11%
Massachusetts	1,592	1,625	2%
Michigan	2,883	3,131	9%
Minnesota	980	1,058	8%
Mississippi	1,063	1,105	4%
Missouri	1,636	1,799	10%
Montana	140	158	13%
Nebraska	401	433	8%
Nevada	406	459	13%
New Hampshire	193	219	13%
New Jersey	2,781	3,033	9%
New Mexico	448	466	4%
New York	5,863	6,199	6%
North Carolina	2,512	2,712	8%
North Dakota	136	127	-7%
Ohio	3,483	3,865	11%

APPENDIX C
INCIDENCE INCREASE (DECREASE) FROM END YEAR 1997 AND
END YEAR 1998

Patients' Residence	Initiated ESRD Therapy 1997	Initiated ESRD Therapy 1998	% Difference
Oklahoma	901	987	10%
Oregon	618	649	5%
Pennsylvania	3,959	4,321	9%
Rhode Island	267	301	13%
South Carolina	1,399	1,507	8%
South Dakota	194	199	3%
Tennessee	1,729	1,752	1%
Texas	5,794	6,323	9%
Utah	267	336	26%
Vermont	120	116	-3%
Virginia	2,264	2,319	2%
Washington	1,023	1,075	5%
West Virginia	614	612	0.00
Wisconsin	1,212	1,343	11%
Wyoming	69	74	0.07
		74	
Total United States	79,880	86,079	8%
American Samoa	7	9	29%
Guam	77	73	-5%
Puerto Rico	974	1,062	9%
Saipan	16	22	38%
Virgin Islands	42	35	-17%
Unknown		7	
Total US and Territories	80,996	87,287	8%
Outside US		14	
Total New ESRD	80,996	87,301	8%

Source: 1998 Network Annual Reports

APPENDIX D
INCIDENCE OF DIALYSIS POPULATION BY AGE AND NETWORK
DECEMBER 31, 1998

Network	0-19	20-29	30-39	40-49	50-59	60-69	70-79	≥ 80	Unk	Total
1	38	79	181	303	496	781	1035	556	0	3,469
2	75	184	390	731	1072	1407	1479	752	0	6,090
3	25	95	235	417	691	973	1043	501	0	3,980
4	57	111	278	492	656	1143	1398	563	0	4,698
5	61	157	409	694	924	1261	1335	529	10	5,380
6	78	247	500	931	1336	1650	1498	567	2	6,809
7	40	116	321	539	773	1126	1474	817	0	5,206
8	57	169	307	602	828	1087	1001	392	0	4,443
9	78	173	464	733	1097	1668	1901	814	6	6,934
10	60	125	287	468	678	929	1139	534	0	4,220
11	77	164	379	730	957	1302	1589	685	0	5,883
12	52	115	243	402	553	826	962	455	0	3,608
13	58	120	263	504	703	885	787	302	0	3,622
14	101	235	475	905	1210	1573	1401	484	4	6,388
15	61	106	264	427	674	877	922	346	1	3,678
16	36	72	171	269	394	495	511	236	0	2,184
17	51	122	255	482	703	968	1016	508	13	4,118
18	74	206	361	680	983	1419	1669	831	0	6,223
Total	1,079	2,596	5,783	10,309	14,728	20,370	22,160	9,872	36	86,933
% Total	1%	3%	7%	12%	17%	23%	25%	11%	0%	

Source: 1998 Network Annual Reports

APPENDIX E
1998 ESRD PREVALENCE OF PATIENTS BY RACE IN
NETWORK RECEIVING TREATMENT

Network	Black	White	Asian/ Pacific Islander	Native American	Other	Unknown	Total
1	1,812	7,368	153	31	186	56	9,606
2	7,525	9,161	599	121	1,423	0	18,829
3	3,568	5,296	163	28	2,339	0	11,394
4	4,360	7,754	45	30	170	26	12,385
5	9,462	5,673	245	0	211	274	15,865
6	14,892	6,449	193	348	399	169	22,450
7	5,615	8,304	190	37	122	0	14,268
8	9,136	5,136	73	66	24	0	14,435
9	5,992	10,916	64	73	264	42	17,351
10	4,841	5,504	183	36	421	6	10,991
11	5,033	9,649	224	484	111	0	15,501
12	2,760	6,575	86	105	7	0	9,533
13	5,897	4,228	68	430	76	0	10,699
14	6,160	6,864	260	67	5,936	187	19,474
15	932	7,051	237	1,547	238	51	10,056
16	617	4,858	425	254	44	0	6,198
17	2,170	6,188	3,409	106	0	29	11,902
18	3,505	11,914	2,082	118	289	0	17,908
Total	94,277	128,888	8,699	3,881	12,260	840	248,845
%Total	38%	52%	3%	2%	5%	0%	

Source: 1998 ESRD Network Annual Reports. Patient numbers are derived from those patients receiving treatment

APPENDIX F
1998 ESRD INCIDENCE OF PATIENTS BY RACE IN
NETWORK RECEIVING TREATMENT

Network	Black	White	Asian/ Pacific Islander	Native American	Other	Unknown	Total
1	483	2,845	44	5	68	24	3,469
2	1,952	3,467	197	25	449	0	6,090
3	1,014	1,854	49	1	1,062	0	3,980
4	1,159	3,414	34	8	65	18	4,698
5	2,613	2,589	70	0	52	56	5,380
6	3,785	2,763	36	49	137	39	6,809
7	1,488	3,600	63	9	46	0	5,206
8	2,270	2,126	21	13	12	1	4,443
9	1,639	5,059	22	49	143	22	6,934
10	1,510	2,385	65	19	234	7	4,220
11	1,340	4,264	71	162	46	0	5,883
12	780	2,726	23	24	55	0	3,608
13	1,654	1,761	19	148	39	1	3,622
14	1,609	2,788	93	23	1,864	11	6,388
15	274	2,838	88	361	97	20	3,678
16	177	1,787	121	80	19	0	2,184
17	622	2,401	1,026	51	0	18	4,118
18	1,039	4,383	663	22	116	0	6,223
Total	26,956	56,837	5,088	1,104	4,504	228	86,933
%	31%	65%	6%	1%	5%	0%	

Source: 1998 ESRD Network Annual Reports. Patient numbers are derived from those patients receiving treatment

APPENDIX G
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
- Tuberos sclerososis
- 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

APPENDIX H
1998 ESRD INCIDENCE BY PRIMARY DIAGNOSIS

Network	Diabetes	Hypertension	Glomerulonephritis	Cystic Kidney Disease	Other Causes	Unknown	Total
1	1,351	805	421	143	719	30	3,469
2	2,437	1,266	640	145	997	605	6,090
3	1,963	1,008	387	97	525	0	3,980
4	1,923	1,152	583	113	920	7	4,698
5	2,243	1,603	639	169	524	202	5,380
6	2,988	1,912	598	185	980	146	6,809
7	1,978	1,633	478	144	757	217	5,206
8	1,872	1,492	374	117	588	0	4,443
9	3,167	1,506	762	165	1,320	14	6,934
10	1,550	1,269	375	87	836	103	4,220
11	2,541	1,502	491	153	940	256	5,883
12	1,561	990	340	191	401	125	3,608
13	1,662	1,115	347	123	271	104	3,622
14	3,233	1,409	637	191	871	47	6,388
15	1,854	639	415	163	427	180	3,678
16	938	419	301	141	297	88	2,184
17	1,924	827	585	162	604	16	4,118
18	2,948	1,758	599	131	787	0	6,223
Total	38,133	22,305	8,972	2,620	12,764	2,140	86,933
% of Total	43.86%	25.66%	10.32%	3.01%	14.68%	2.46%	

Source: 1998 Network Annual Reports

APPENDIX I
1998 INCIDENCE OF PATIENTS BY GENDER IN NETWORK RECEIVING TREATMENT

Network	Male	Female	Unknown	Total
1	1,896	1,573	0	3,469
2	3,299	2,791	0	6,090
3	2,192	1,788	0	3,980
4	2,585	2,113	0	4,698
5	2,801	2,579	0	5,380
6	3,317	3,399	93	6,809
7	2,890	2,316	0	5,206
8	2,203	2,240	0	4,443
9	3,564	3,354	16	6,934
10	2,248	1,972	0	4,220
11	3,175	2,708	0	5,883
12	1,953	1,655	0	3,608
13	1,844	1,778	0	3,622
14	3,326	3,062	0	6,388
15	2,028	1,649	1	3,678
16	1,214	970	0	2,184
17	2,214	1,891	13	4,118
18	3,341	2,882	0	6,223
Total	46,090	40,720	123	86,933
% Total	53%	47%	0%	

Source: 1998 Network Annual Reports

APPENDIX J
1998 PREVALENCE OF PATIENTS BY GENDER IN NETWORK
RECEIVING TREATMENT

Network	Male	Female	Unknown	Total
1	5,134	4,472	0	9,606
2	10,184	8,645	0	18,829
3	6,440	4,954	0	11,394
4	6,639	5,746	0	12,385
5	8,329	7,460	76	15,865
6	10,777	11,308	365	22,450
7	7,774	6,494	0	14,268
8	7,071	7,364	0	14,435
9	9,057	8,277	17	17,351
10	5,748	5,242	1	10,991
11	8,273	7,228	0	15,501
12	4,967	4,566	0	9,533
13	5,456	5,243	0	10,699
14	9,746	9,728	0	19,474
15	5,313	4,738	5	10,056
16	3,375	2,823	0	6,198
17	6,129	5,761	12	11,902
18	9,370	8,538	0	17,908
Total	129,782	118,587	476	248,845
% Total	52%	48%	0%	

Source: 1998 Network Annual Reports

APPENDIX K
IN-CENTER DIALYSIS PATIENTS BY NETWORK MODALITY
DECEMBER 31, 1998

NETWORK	Hemodialysis	Peritoneal Dialysis
1	8,138	30
2	16,214	14
3	9,851	1
4	11,099	9
5	13,955	45
6	19,785	0
7	12,489	2
8	12,908	5
9	14,744	30
10	9,788	12
11	13,366	0
12	7,821	0
13	9,368	4
14	17,484	18
15	8,844	2
16	5,052	13
17	10,389	12
18	16,027	13
Total	217,322	210

Source: 1998 Network Annual Reports

APPENDIX L
HOME DIALYSIS PATIENTS BY NETWORK
DECEMBER 31, 1998

NETWORK	Hemodialysis	CAPD	CCPD	Other PD	Total
1	50	583	707	1	1341
2	145	1,038	781	0	1,964
3	56	657	829	0	1,542
4	59	511	624	0	1,194
5	148	860	810	10	1,828
6	176	1,433	1,141	18	2,768
7	162	508	726	0	1,396
8	124	746	637	10	1,517
9	65	1,636	860	11	2,572
10	65	716	408	2	1,191
11	75	1,350	709	1	2,135
12	136	929	647	0	1,712
13	22	607	420	2	1,051
14	66	796	930	2	1,794
15	62	578	565	1	1,206
16	220	558	340	15	1,133
17	25	685	746	0	1,456
18	17	1,078	837	1	1,933
Total	1,673	15,269	12,717	74	29,733

Source: 1998 Network Annual Reports

APPENDIX M
1997 AND 1998 DIALYSIS MODALITY: IN CENTER

Network	HEMO			PD		
	1997	1998	% Change	1997	1998	% Change
1	7,526	8,138	8%	20	30	50%
2	15,174	16,214	7%	35	14	-60%
3	8,914	9,851	11%	20	1	-95
4	10,291	11,099	8%	44	9	-80%
5	13,108	13,955	6%	59	45	-24%
6	18,161	19,785	9%	5	0	0
7	11,596	12,489	8%	15	2	-87%
8	11,735	12,908	10%	12	5	-58%
9	13,065	14,744	13%	19	30	58%
10	9,096	9,788	8%	18	12	-33%
11	12,128	13,366	10%	0	0	0%
12	7,001	7,821	12%	0	0	0%
13	8,811	9,638	9%	0	4	n/a
14	16,062	17,484	9%	58	18	-69%
15	7,960	8,844	11%	10	2	-80%
16	4,631	5,052	9%	17	13	-24%
17	9,540	10,389	9%	13	12	-8%
18	14,718	16,027	9%	4	13	225%
Total	199,517	217,592	9%	349	210	-40%

Source: 1998 Network Annual Reports

APPENDIX N
1997 and 1998 DIALYSIS MODALITY: SELF-CARE SETTING- HOME

Network	HEMO			CAPD			CCPD			OTHER PD		
	1997	1998	% Change	1997	1998	% Change	1997	1998	% Change	1997	1998	% Change
1	70	50	-29%	691	583	-16%	708	707	0%	0	1	n/a
2	146	145	-1%	1,182	1,038	-12%	763	781	2%	0	0	0
3	64	56	-13%	781	657	-16%	848	829	-2%	0	0	0
4	82	59	-28%	636	511	-20%	597	624	5%	0	0	0
5	152	148	-3%	922	860	-7%	753	810	8%	5	10	100%
6	158	176	11%	1,601	1,433	-10%	1,059	1,141	8%	15	18	20%
7	195	162	-17%	609	508	-17%	666	726	9%	1	0	-100%
8	140	124	-11%	885	746	-16%	545	637	17%	27	10	-63%
9	125	65	-48%	1,725	1,636	-5%	827	860	4%	18	11	-39%
10	100	65	-35%	763	716	-6%	365	408	12%	5	2	-60%
11	89	75	-16%	1,576	1,350	-14%	694	709	2%	2	1	-50%
12	127	136	7%	1,029	929	-10%	667	647	-3%	0	0	0%
13	39	22	-44%	659	607	-8%	428	420	2%	2	2	0%
14	71	66	-7%	868	796	-8%	891	930	4%	5	2	-60%
15	86	62	-28%	558	578	4%	557	565	1%	16	1	-94%
16	272	220	-19%	628	558	-11%	312	340	9%	14	15	7%
17	23	25	9%	738	685	-7%	772	746	-3%	0	0	0
18	20	17	-15%	1,225	1,078	-12%	816	837	3%	0	1	n/a
Total	1,959	1,673	-15%	17,076	15,269	-11%	12,268	12,717	4%	110	74	-33%

Source: 1998 Network Annual Reports

APPENDIX O
NUMBER OF RENAL TRANSPLANTS PERFORMED
CALENDAR YEAR 1998

NETWORK	Total Kidney Transplants	Patients Waiting for Kidney Transplants*
1	628	2,112
2	841	3,999
3	314	1,443
4	832	2,580
5	853	3,566
6	788	2,224
7	663	1,265
8	671	2,030
9	972	1,737
10	557	2,157
11	1,375	3,505
12	657	1,126
13	393	1,304
14	954	1,835
15	629	1,237
16	445	907
17	662	1,965
18	978	3,240
Total	13,212	38,232

Source: 1998 Network Annual Reports

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

APPENDIX P
RENAL TRANSPLANT RECIPIENTS BY DONOR SOURCE
CALENDAR YEAR 1998

NETWORK	Cadaver	Living Related	Living Unrelated	Unknown	Total
1	339	221	68	0	628
2	549	242	50	0	841
3	214	87	13	0	314
4	671	141	19	1	832
5	467	249	137	0	853
6	573	188	27	0	788
7	536	108	19	0	663
8	454	175	42	0	671
9	731	241	0	0	972
10	350	207	0	0	557
11	818	420	137	0	1,375
12	461	157	39	0	657
13	275	98	20	0	393
14	681	228	45	0	954
15	368	188	44	29	629
16	278	134	33	0	445
17	444	167	51	0	662
18	650	247	81	0	978
Total	8,859	3,498	825	30	13,212

Source: 1998 Network Annual Reports

APPENDIX Q
1998 NETWORK QUALITY IMPROVEMENT PROJECTS

TOPIC	NETWORK
ANEMIA	
Cooperative Anemia Project	TransAtlantic Renal Council (3)
A Systems - Based Approach to Quality Improvement	Renal Network of the Upper Midwest, Inc. (11)
HEMODIALYSIS ADEQUACY	
Adequacy of Dialysis	ESRD Network Organization #4
Improving the Adequacy of Hemodialysis	Mid-Atlantic Renal Coalition (5)
Hemodialysis Adequacy	Network 8, Inc.
Hemodialysis Central Venous Catheter	The Renal Network, Inc. (9/10)
Adequacy of Hemodialysis	ESRD Network Organization #13
Improving Adequacy of Hemodialysis in Texas	ESRD Network of Texas, Inc. (14)
Reducing the Rate of Hemodialysis Access Infection	Northwest Renal Network (16)
Improving Adequacy of Hemodialysis in Northern California ESRD Patients	TransPacific Renal Network (17)
PERITONEAL DIALYSIS ADEQUACY	
Improving Peritoneal Dialysis Adequacy Measures	ESRD Network of New York, Inc. (2)
PD Intervention Project	Southeastern Kidney Council, Inc. (6)
Peritoneal Dialysis Adequacy	Network 8, Inc.
Peritoneal Dialysis Prescription Adequacy	The Renal Network, Inc. (9/10)
Peritoneal Dialysis Adequacy	ESRD Network 12
Peritoneal Dialysis Adequacy	Intermountain ESRD Network (15)
Improving Adequacy and Nutrition for Peritoneal Dialysis Patients in Network 17	TransPacific Renal Network (17)
IMMUNIZATIONS	
Texas ESRD Immunization Cooperative Project	ESRD Network of Texas, Inc. (14)

APPENDIX Q
1998 QUALITY IMPROVEMENT PROJECTS

TOPIC	NETWORK
VASCULAR ACCESS	
Increasing the Utilization of Permanent Access in Incident ESRD Patients	ESRD Network of New England, Inc. (1)
Early Detection of Venous Stenosis in AV Grafts to Prevent Thrombosis	ESRD Network of New York (2)
Vascular Access	TransAtlantic Renal Council (3)
Cooperative ESRD Vascular Access Study	ESRD Network of Florida (7)
Vascular Access	ESRD Network 12
Early Detection of Venous Stenosis in AV Grafts to Prevent Thrombosis	ESRD Network Organization #13
Increasing and Maintaing AV Fistula Rates	Southern California Renal Disease Council, Inc. (18)
NEPHROLOGY CARE	
Early Referral to Nephrology Care	ESRD Network Organization #4
Strategies for Managing the Continuum of Care in the ESRD Patient	Renal Network of the Upper Mid-West (11)
HEPATITIS B VACCINATION	
	ESRD Network of Florida (7) Network #12 Southeastern Kidney Council (6) Southern California Renal Disease Council, Inc. (18)
INFLUENZA IMMUNIZATION	
	ESRD Network of New England, Inc. (1) Mid-Atlantic Renal Coalition (5) Southeastern Kidney Council (6) Renal Network of the Upper Mid-West (11) Intermountain ESRD Network (15)

Source: 1998 Network Annual Reports

APPENDIX R
1998 NETWORK SPECIAL STUDY PROJECTS

Network	Special Study
1	Connecticut Bacteremia Project
1	Increasing the Utilization of Permanent Access in Incident ESRD Patients
4	Implementation of the DOQI Guidelines
4	Network 4 Recommended Pediatric Scope of Care Guidelines
5	Increasing Educational Efforts to Promote Living Donor Kidney Transplant
6	Family History Study
6	Racial Variation in Autosomal Dominant Polycystic Kidney Disease
6	Fetal and Early Life Events and the Development of ESRD
7	Home Hemodialysis Training Demonstration Project
7	Customer Contacts and Resolving Grievances
7	Transplant Rate Improvement Project
9/10	Network Core Indicators: 100% Sampling
11	Medical Review Committee Follow-Ups
11	Peritoneal Dialysis Review
15	Network Specific Standard Mortality Ratios

Source: 1998 Network Annual Reports

APPENDIX S
VOCATIONAL REHABILITATION
PATIENTS AGED 18-55 YEARS AS OF DECEMBER 31, 1998

NETWORK	Number of Patients 18-55 Years	Referrals to Vocational Rehabilitation	Patients Employed or Attending School Full or Part time	Facilities Offering Dialysis Shift after 5 pm
1	2,884	116	900	70
2	6,549	505	1,941	119
3	3,897	434	1,564	66
4	3,063	198	818	37
5	5,711	942	1,544	58
6	6,067	629	1,195	31
7	5,123	379	1,085	32
8	4,756	125	911	32
9	6,191	186	1,578	105
10	3,870	243	772	45
11	5,154	517	1,343	63
12	2,867	214	1,032	31
13	4,152	573	834	38
14	8,070	605	1,869	40
15	3,750	461	1,294	47
16	2,389	384	744	51
17	4,337	340	1,058	55
18	6,724	553	1,607	74
Total	85,554	7,404	22,089	978

Source: 1998 Network Annual Reports

LIST OF ACRONYMS

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

Appendix
Deaths of Dialysis Patients
Calendar Year 1998

NETWORK	Total Deaths
1	2,395
2	3,964
3	3,011
4	2,998
5	3,663
6	4,123
7	3,785
8	3,210
9	4,530
10	2,524
11	3,891
12	2,437
13	2,448
14	4,020
15	2,304
16	1,473
17	2,740
18	4,110
Total	84,626

Source: 1998 Network Annual Reports