## 2002 Annual Report

## **ESRD Network Area #3**

Contract Number: 500-00-NW03

### Submitted to:

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### **PREFACE**

On behalf of all chronic renal care facilities within Network 3, I am pleased to submit this 2002 annual report of performance and achievements.

All facility staff are to be commended for their efforts to meet goals and participate in the various projects and activities of the network. Progress continues to be made in dialysis adequacy, anemia management and rehabilitation. Data timeliness and accuracy show the results of improvement efforts and provide necessary information for quality improvement project development and federal program management. Such sustained progress serves as a testament to the dedication and commitment of professional staff in the face of facility pressures in staffing, mergers and increased consumer demand for services.

Current efforts directed toward decreasing the number of catheter accesses used in dialysis and an increased number of native fistulas show promise. All recognize the difficulties inherent in such a project but there is little doubt that it will have long-term benefits for consumers.

I want to acknowledge the contribution of all the voluntary board and committee members who worked so assiduously in the development of network activities and the oversight of improvement efforts. Such service is appreciated and brings satisfaction in reviewing results that impact the lives and medical status of renal consumers of care.

Finally I would like to express our appreciation to network staff who coordinate and support all the administrative work we perform.

We look forward to the continuation of this partnership with the Centers for Medicare & Medicaid Services, facility staff, consumers, departments of health and other interested agencies as we begin another phase of health care quality improvement projects.

Jorge Weber, MD President, Board of Trustees June 19, 2003

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### 2. INTRODUCTION

### A. NETWORK DESCRIPTION

NEW JERSEY
GEOGRAPHY AND GENERAL POPULATION CHARACTERISTICS

New Jersey contains 8,215 square miles with 21 counties and 567 municipalities. Its highest elevation is 1,803 feet at High Point and its lowest is sea level at the Atlantic Ocean with an average elevation of 250 feet. Although New Jersey is geographically one of the smallest states in the nation (it ranks 46<sup>th</sup>), it is the ninth most populous, with approximately 8.4 million residents according to the Census 2000. There were 1,143.9 inhabitants per square mile of land area - the most densely populated state in the nation.

The majority of residents reside in metropolitan areas with only 10.6% in rural areas. The U.S. Census Bureau categorized only New Jersey and the District of Columbia as 100% metropolitan areas. The only area to surpass New Jersey in degree of urbanization is California (92.6%) which has the largest resident state population (34.5 million). However, California has a population density of only 221.2/sq. mi.

Approximately 1.1 million (13.2%) of New Jersey's population base is aged 65 and older. The highest concentration of those age 65 or older is found in Ocean and Cape May counties. Nationally, fifteen other states had a higher percentage of those 65 and older.

The population is reported to be 73% white, 14% black, 6% Asian and 7% other. Most of the population growth in New Jersey during the last decade occurred in minority populations; Hispanics sustained the largest increase. Hispanics now constitute approximately 12.4% of the population within New Jersey and Hispanics of Puerto Rican descent comprise more than 43% of all Hispanic residents. The largest increase of Hispanic residents occurred in Hudson and Passaic counties.

New Jersey is surpassed by only 7 other states in the proportion of resident Hispanic or Latino residents. New Mexico (42.1%), California (32.4%), Texas (32%), Arizona (25.3%), Nevada (19.7%), Florida (16.8%), and New York (15.1%) surpass New Jersey's 13.3% resident Hispanics and Latinos.

New Jersey ranked sixth in the estimated number of resident undocumented immigrants with 135,000 individuals (1996). In 1998 the US Census Bureau reported the admission to New Jersey of 35,091 immigrants from other countries with 4,284 from India, 2,478 from the Dominican Republic, 1,648 from the Philippines, 1,318 from China, 1,037 from, Jamaica, 772 from Mexico, 437 from Cuba, and fewer from other countries. New Jersey was surpassed in the number of immigrants only by the states of California, New York, Florida and Texas.

Not all age groups are equally constituted. The under 5 age group constitutes 7% of the resident population; the 5-17 age group accounts for 18% of the population; the 18-24 group for 8%, the 25-44 age group for 14%; the 45-54 for 14%, the 55 to 64 group for 9% and the 65+ age group for 13% of the population. It is important to note that from 1990 - 1998 the 85 and older age group increased by 38%. This growth in the aged population among the residents of New Jersey contributes to the increase in the mean age of consumers presenting for renal therapy due to end-stage disease.

New Jersey's birth rate of 14.1 is lower than the national rate of 14.7/1,000 estimated population as is its fertility rate (per 1,000 women aged 15-44 years estimated) 65.8 vs. 67.5. Death rates by cause show the leading cause to be heart disease followed by cancer, cerebrovascular diseases, chronic obstructive pulmonary diseases, diabetes mellitus, accidents, and HIV. The death rate is 9.2 (per 1,000) while the national rate is 8.7.

The marriage rate (per 1,000 population) in 2001 was 6.6, higher than the 1998 rate of 5.9, but still lower than the national rate of 8.4; divorce rates were reported to be 3.5 in New Jersey and 4.0 nationally for 2001.

In 1998, the latest available data showed New Jersey per capita personal health care expenditures (\$2,900/resident) were exceeded only by the states of Connecticut (\$3,298), New York (\$3,255), Pennsylvania (\$2,941) and Rhode Island (\$2,937). The major portion was expended on hospital services followed by physician services, drugs and non-durables, nursing home care, other professional services, dental services, home health care, other personal health care and medical durables.

Health insurance coverage did not extend to 12.6% of the New Jersey population in 2000. The national average was 14.0%. Children not covered in New Jersey was 9.3% with a national average of 11.6%.

Excluding doctors of osteopathy and federal employees, New Jersey in 2000 had 298 physicians per 100,000 population, a rate exceeded only by the states of Connecticut, Massachusetts, New York, Maryland, Vermont, and Rhode Island. The national rate is 251, unchanged from two prior years. Twenty-six states surpassed New Jersey with its rate of 805 nurses per 100,000 population. In 2000, the national rate/100,000 for physicians was 251 and in 1999 for nurses it was 789, a significant decrease from 1998's 828.

Although mergers and acquisitions have increased in recent years, in 2000 New Jersey had 80 acute care hospitals compared to 95 in 1990. The number of organizational affiliations has increased so that the institutional count will vary depending on the selection criterion utilized.

The state continues to have one of the highest AIDS caseloads following New York, California, Florida and Texas.

NJ Adult/Adolescent AIDS Cases Reported 7-01 to 6-02 and Cumulative Totals A/O 6-02

Age Group	7/01 – 6/02		Age Group 7/01 – 6/02 Cumulative Total		al
(at	No.	%	No.	%	
diagnosis)					
13-19	13	1	201	0	
20-29	141	9	5,996	14	
30-39	541	35	19,768	46	
40-49	570	37	12,413	29	
49+	276	18	4,673	11	
Total	1,930	100	43,051	100	

In 2002 the Centers for Disease Control reported the lowest national tuberculosis rate(5.2) in the United States since reporting began in 1953. New Jersey's case rate in 2002 was 6.2 (530 cases). Five other states had higher case rates than New Jersey: Hawaii (11.5), California (9.0), New York (7.5), Texas (7.1), and Florida (6.5). New Jersey's case rate in 1998 (640 cases) and 1999 (571 cases) was 7.9 and 7.0, respectively; nationally, the rates were 6.8 and 6.4.

Currently, two sub-population groups account for approximately 75% of tuberculosis cases: foreign-born persons and US-born non-Hispanic black population. The most frequent birth countries are Mexico, Philippines, Vietnam, India, China, Haiti and South Korea.

The percentage of New Jersey residents with advanced educational degrees (8.8%) exceeds the national average of 7.2%. Eight states exceeded the New Jersey rate. In 2000, 87.3% were high school graduates and 30.1% had bachelor's degrees or higher levels of attainment.

In 2001, the average elementary and secondary school teacher's salary in New Jersey was \$53,300. New Jersey was surpassed by only two other states for secondary salaries: California and Connecticut (\$54.8 and \$54.0). The national average was \$43,300 in 2001. Only Alaska (\$2,129), Connecticut (\$1,864), Minnesota (\$1,673), and New York (\$1,749) exceeded New Jersey's average 2000 per capita student expenditure (\$1,579).

The New Jersey unemployment rate for 2002 was recorded to be 5.8%. Variations among the 21 counties ranged from 3.6% to 9.6%.

New Jersey Unemployment Rate

COUNTY	1990	1995	1999	2000	2002
	(%)	(%)	(%)	(%)	
Atlantic	6.2	8.6	7.2	5.7	6.6
Bergen	3.9	5.8	3.7	3.1	5.0
Burlington	4.6	5.0	3.3	2.9	4.6
Camden	5.9	6.4	4.6	3.9	5.8
Cape May	7.7	12.1	10.1	8.6	9.6
Cumberland	7.5	9.8	8.6	7.2	8.5
Essex	6.3	7.7	5.7	4.7	7.3
Gloucester	5.6	6.5	4.5	3.8	5.2
Hudson	7.3	9.3	7.2	5.7	8.1
Hunterdon	2.7	3.2	2.1	1.7	3.6
Mercer	4.4	5.4	4.0	3.0	5.1
Middlesex	4.5	5.5	3.8	3.1	5.4
Monmouth	4.1	5.4	4.0	3.2	5.3
Morris	3.2	4.3	2.8	2.3	4.4
Ocean	5.1	6.2	4.6	3.9	5.4
Passaic	6.4	8.6	6.2	5.0	7.5
Salem	5.3	6.5	4.7	4.4	6.4
Somerset	2.9	3.8	2.5	2.1	4.4
Sussex	4.2	5.7	3.5	2.9	5.1
Union	5.4	6.5	4.8	4.0	6.4
Warren	4.3	5.7	4.2	3.1	5.3
All	5.1	4.6	4.6	3.8	5.8

The average annual wage in New Jersey (2000) was \$43,691. Disposable personal income rankings showed New Jersey higher than all states except Connecticut and Massachusetts. New Jersey's median household income in 2000 (\$51,739) was third highest in the country.

The 2001 New Jersey per capita personal income (\$38,153) reported by the Bureau of Economic Analysis at the US Department of Commerce showed variation among counties:

New Jersey Per Capita Personal Income (\$)

COUNTY	1996	1997	1999	2001
Atlantic	29,415	30,187	32,086	31,550
Bergen	40,676	43,123	48,017	51,900
Burlington	26,669	27,849	30,747	34,683
Camden	25,518	26,500	28,035	30,496
Cape May	25,759	26,419	29,455	31,412

COUNTY	1996	1997	1999	2001
Cumberland	20,662	21,663	22,894	23,616
Essex	31,411	32,581	34,824	37,134
Gloucester	23,374	24,340	27,077	29,243
Hudson	24,233	24,943	27,662	28,584
Hunterdon	37,675	39,830	44,833	53,815
Mercer	33,893	36,598	39,626	42,317
Middlesex	29,544	30,881	34,267	36,691
Monmouth	32,401	33,952	37,267	42,028
Morris	41,018	42,913	49,957	58,151
Ocean	25,113	25,725	27,694	30,023
Passaic	24,426	25,560	27,559	29,355
Salem	24,374	25,162	27,178	29,149
Somerset	44,089	46,392	52,078	55,580
Sussex	27,134	28,162	30,270	34,628
Union	33,090	35,157	38,487	41,149
Warren	25,466	26,687	29,079	31,323
US	24,164	25,288	35,612	30,271

The 1998-2000 average of the New Jersey population estimated to be below the poverty level was 8.1% while the national rate was 11.9%. Five states had lower rates than New Jersey. In 1980, 9.0% of New Jersey's population was reported to be below the poverty level; the national rate was 13.0%.

Average retired workers monthly benefit dollars in New Jersey were the highest of any state in 2001 at \$965/mo. The average weekly unemployment benefit in New Jersey was third highest of all states at \$309, exceeded by Massachusetts (\$335) and Washington (\$311).

### **INCIDENCE OF RENAL DISEASE IN NEW JERSEY**

In 2000, all but three states had an adjusted end-stage renal disease incidence rate that exceeded 200 per million population. The 2002 Annual Data Report of the United States Renal Data System (USRDS) listed thirteen states areas with higher 2000 age, race, sex-adjusted incidence rates than New Jersey compared to three states in 1999. The New Jersey adjusted incidence rate in 2000 was reported to be 332/million (359/million in 1999). (Annual incidence rates do not have the stability that averages for a three or five-year period would exhibit.)

The USRDS published adjusted annual incidence rates from 1991-2000. Each year New Jersey showed an increase demonstrating a steady trend: 241, 253, 263, 294, 308, 304, 327, 340, 359, 332.

Adjusted incidence rates for 2000 reported in network-area aggregates showed that Network #3 was surpassed by seven other areas compared to the 1999 analysis which showed New Jersey surpassed only by the Texas (single-state) network.

The average age of consumers starting therapy in 1999 was 61compared with the average age in 1990 of 58.

According to the ESRD Facility Survey in 2002, 3,155 New Jersey consumers initiated therapy in New Jersey facilities -a slight decrease compared with 2001 new cases. Older people, in particular those over 65 years of age, continued to represent the largest and fastest growing age group of ESRD beneficiaries. Of the total new starts in 2002, 56% were 65 years or older and 45% were 70 years or older. Nineteen percent were eighty years or older. These percentages varied little from the prior year.

Other characteristics of the New Jersey incident population closely mirror national new case renal statistics: 55% were male and 45% female; 32% black and 62% white.

Among incident cases the most frequently reported primary diagnoses were diabetes (43%) and hypertension (30%). Collectively, these two diagnoses represented the largest proportion of new cases in 2002.

### RENAL THERAPY IN NEW JERSEY

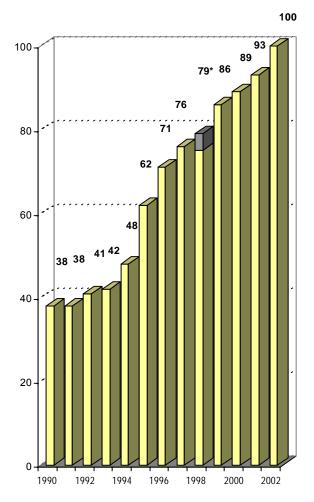
The New Jersey Department of Health regulated the approval of all new ESRD providers and expansion of services through the certificate of need process until January 1992. Since that time, chronic ambulatory dialysis is no longer subject to certificate of need requirements. The number of facilities increased from 38 in 1991 to 100 (not including a non-Medicare certified ESRD veterans hospital) in 2002. This is a 264% increase.

In 2002, the total approved station count rose to 1,714 from the 2000 count of 1,593. During 2002, the number of Medicare-certified facilities rose from 93 to 100. Most facilities are no longer hospital-based since 73 free-standing clinics provide service. One veterans administration hospital, which is not a participant in the Medicare program, treats its special population.

Almost all facilities were approved to provide staff-assisted hemodialysis except for a few peritoneal-only units; 63% (n=63) offered CAPD/CCPD training; 17% (n=17) offered hemodialysis home training. These services reflect the choices among patient and physician preferences for therapy and were available throughout the state.

Staff-assisted hemodialysis, favored by 93% of ESRD consumers (83% in 1996), remained the dominant therapy in the state. Continuous cycling peritoneal dialysis (CCPD) became the dominant home therapy (n=412) with continuous ambulatory peritoneal dialysis (CAPD) the second most prevalent (n=233). Home hemodialysis accounted for only 18 cases statewide.

### Number of New Jersey ESRD Facilities Network #3



Source: HCFA Approval Letters

The national distribution of modalities reported for 2000 was the following: facility hemodialysis, 89%; home hemodialysis, 0.5%; CAPD/CCPD, 8.5%; other and uncertain, 2%; transplant 27.4% (Source: USRDS 2002 Annual Data Report)

### **PREVALENCE**

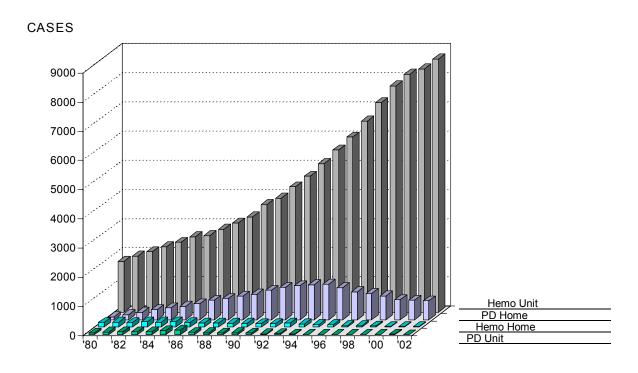
The USRDS published adjusted annual point prevalence rates/million population for 1991-2000 by state. New Jersey results were 872, 937, 988, 1069, 1135, 1188, 1244, 1306, 1373, 1384.

The prevalent caseload increased 3% over the prior year. Of the approximately 9,338 prevalent consumers receiving dialysis in New Jersey, 55% were male and 45% female. Forty-one percent of the population on dialysis was black, 50% white, with other racial groups constituting the remainder.

Thirty-six percent of the consumers receiving chronic dialysis were 70 years or older, and 23% were within the 60-69 age group. Fifty-nine percent of the prevalent consumers receiving dialytic therapy in New Jersey during 2002 were aged sixty years or older. The aged population continues to be the fastest growing segment both receiving long-term chronic care and initiating treatment.

Diabetes was the most frequently reported primary disease of all prevalent consumers on dialysis at 39%. Hypertension followed at 29% of the caseload and glomerulonephritis ranked third at 14%. The majority of consumers (66%) in treatment were diagnosed with either diabetic nephropathy or hypertensive disease-- the two leading national risk factors for ESRD.

# Dialysis Modality/Setting Distribution: New Jersey 1980-2002

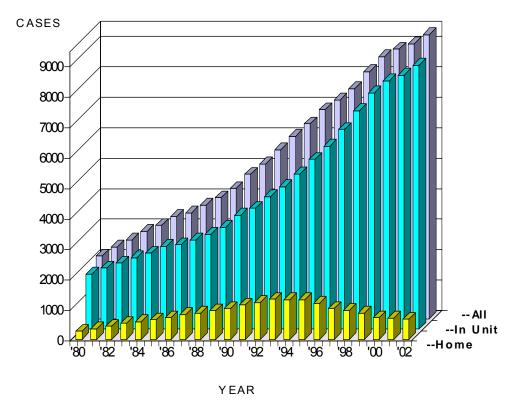


YEAR

Source: ESRD MIS ESRD Facility Survey, HCFA-2744

Trans-Atlantic Renal Council

# Setting Distribution of New Jersey Dialysis Cases 1980 - 2002



Source: Network #3 database, HCFA-2744 Trans-Atlantic Renal Council

### **MORTALITY DATA**

Death notification reports for New Jersey ESRD consumers were analyzed by sex, race, and cause of death. The primary cause of death reported in 2002 continued to be cardiac (50%) which again reflected national data. Infection was reported in 20% of the 2,498 death records received. Of all deaths reported in 2002, 65% were white, 30% black; 53% were male, 47% female. Primary diagnoses among deaths reported were diabetes (43%), hypertension (31%), glomerulonephritis (8%), polycystic disease (1%), and other/unknown.

### **TRANSPLANTATION**

Five renal transplant centers serviced the New Jersey ESRD population with referrals also being made to neighboring New York, Philadelphia, and Maryland. Recent years have seen an inflow for transplantation to New Jersey of neighboring state residents as well. Organ procurement activities were the responsibility of two federally-approved agencies, the New Jersey Organ and Tissue Sharing Network (The Sharing Network) and the Gift of Life Donor Program.

In 2002, 363 transplants were performed in New Jersey at federally-certified ESRD renal transplant centers, an decrease of 6% under 2001 performance. Of the 363 transplant procedures performed within New Jersey, 193 had cadaveric donors and 170 had living donors.

The number of consumers on a waiting list in New Jersey continued to increase to a total of 2,126, 2% higher than the previous year. Unless the donor pool is enlarged, transplantation will not be available to the majority of consumers on the list except, perhaps, after a lengthy waiting period. Alternatively, living donor transplantation may be able to provide some candidates with more timely access to this modality.

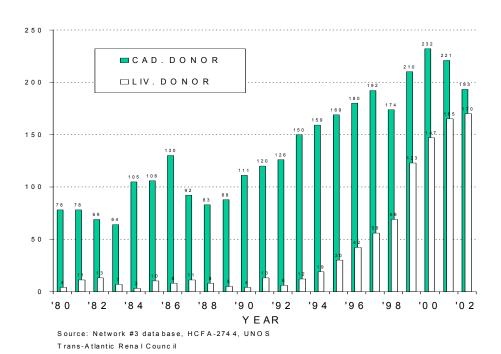
Nationally, transplantation among minority groups occurred at a slower rate reportedly due to cultural factors and problems encountered in genetic matching protocols. New Jersey transplant centers transplanted minority consumers at a rate higher than the national average.

Although kidney donors parallel national data in regard to race categorization (predominantly white females, followed by white males, and ranking last, blacks-male and female), the minority population transplanted appears to be comparatively better served within New Jersey.

As stated above, two federally-approved organ procurement organizations serve New Jersey: The Sharing Network and the Gift of Life Donor Program.

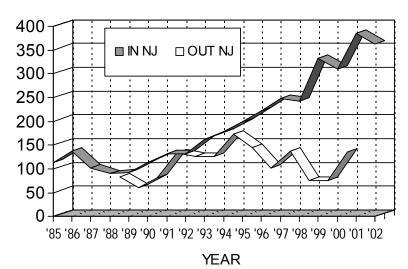
Renal Transplants Performed in New Jersey by Type: 1980-2002

CASES



# New Jersey Residents Transplanted Out of State and Number Performed in New Jersey Renal Centers

### CASES



\*1985-87 out of NJ could not be verified.

Source: Network databse; UNOS data 1994 forward

### PUERTO RICO AND THE VIRGIN ISLANDS

## GEOGRAPHY AND GENERAL POPULATION CHARACTERISTICS

Similar to New Jersey, Puerto Rico is densely populated (1,124/sq. mi.) with land area covering nearly 3,427 square miles and a population of 3.808 million. There were 1,027.9 inhabitants per square mile according to the 2000 census. Between 1990 and 2000, the population increased 8%.

Puerto Rico Population by Age, 2000

Age Group	Population
0-24	1,520,995
25-54	1,513,031
55-64	349,447
65-74	240,951
75-84	136,480
85+	47,706
All	3,808,610

Droughts are one of the naturally occurring hazards to the local population. Sediment buildup (60% storage reduction over the last 50 years) in reservoirs reduced the holding capacity of several major water supplies. Reclamation efforts are underway and should reduce the periodic threat to potable water

supplies. The U.S. Geological Survey works with 15 local agencies to operate a real-time hazard alert network concerned with rainfall, stream flow, lake levels and beach erosion from catastrophic events.

In recent years Puerto Rico has experienced major expansion in the construction and tourism sectors. Construction of housing, commercial buildings and infrastructure (super aqueduct, urban train, highways) contributed to economic development. Some manufacturing plants did expand but the effect of favorable tax benefit elimination is uncertain for the future; Section 936 will be completely phased out in 2005.

The 2000 Census Bureau report showed that the labor force (1.303 million) was distributed among several types of work: 2% were engaged in agriculture, 12% in manufacturing, 18% in trade and 19% in government positions. Approximately 14% were unemployed in 1998, 13.7% in 1999, 11% in 2000.

One in every four Hispanic families lives at the federal poverty level with average earnings well below the U.S. national average. Forty percent of all households rely on some form of public assistance. The average monthly benefit paid to retired workers is \$527. The average annual employee compensation reported by the most recent Bureau of the Census publication (2000) was \$20,064; the average family income was \$33,559.

In 1999 there were 525,000 Medicare enrollees; Medicaid had 1,055,000 enrollees in 1998. The local Health Reform Program covers 1.8 million indigent residents.

The birth rate reported by the U.S. Bureau of the Census in 2000 was 15.2/1,000 population; the death rate (2000) was 7.2/1,000 population. The median age is still 32.1 years. Of the residents, 509,856 (23%) were high school graduates; 418,253 (19%) had a bachelor's degree or higher. The average employee compensation in 2000 was \$21,123; the average family income was \$36,776.

Population characteristics describe basic life choices, such as early acquisition of medical care and the existence of discretionary income to provide adequate housing and nutritional support. Many communities are isolated and lack treated water supplies. The Environmental Protection Agency (EPA) has been working with the local health department's environmental division to provide special water filters, chlorine if needed, and basic education on suitable potable water for drinking.

Health system reform was undertaken to provide universal coverage and eliminate governmental ownership of facilities.

The death rate for HIV (17.6) was second (in ranking) only to Washington, DC. Similarly, the rate for diabetes mellitus (61.5) was the highest among all states and the District of Columbia.

### THE U.S. VIRGIN ISLANDS

The territory of the Virgin Islands consists of 3 islands - St. Thomas, St. Croix and St. John - and about 50 islets, most of which are uninhabited. These islands are located 60 miles southeast of Puerto Rico between the Caribbean Sea and the Atlantic Ocean in the Lesser Antilles chain of the West Indies. It is an unincorporated territory of the United States administered by the Office of Insular Affairs, U.S. Department of the Interior. The governor and lieutenant governor are elected for four-year terms.

The land area covers 134 square miles with an overall population estimated to be 121,000. There were 761 residents/sq. mi. in 1990.

Residents are comprised of people from the West Indies (45% native to Virgin Islands, 29% born elsewhere in West Indies), Puerto Rico (5%), U.S. mainland (13%), and other (8%). Racial composition

in the Virgin Islands is estimated to be 80% black, 15% white and 5% other. Spanish and Creole are spoken in addition to English.

US Virgin Islands Population by Age, 2000

Age Group	Population
0-24	52,542
25-54	45,948
55-64	12,174
65-74	6,468
75-79	1,903
80+	1,882
All	120,917

Source: US Bureau of the Census, International Database.

Approximately 37% of the territory's population resides in urban areas, while 63% is located in rural or suburban developing communities. Forty-six percent of the population resides on the island of St. Thomas. Charlotte Amalie remains the urban center of St. Thomas. Christiansted and Frederiksted are the major towns on St. Croix.

Population density fluctuates among the individual islands. St. Thomas has the highest density with 1,579 persons per sq. mi., St. Croix has 583/sq. mi. and St. John only 118/sq. mi.

There are two international airports in the Virgin Islands; one is on St. Thomas and the other on St. Croix. Transport to St. John is via scheduled ferry from St. Thomas or St. Croix. Cars on the islands use 856 km of paved highways.

The birth rate reported by the U.S. Census Bureau has been declining since the 1970s and is estimated to be 12.9/1,000 population (2000). Similarly, the death rate follows the declining trend and is reported to be less than 5.3/1,000 population. The median age is reported to be 33.4 years which is slightly higher than Puerto Rico's 32.1.

Of the 65,603 residents 25 years and older, 17,044 (26%) were high school graduates and 10,989 (17%) held a bachelor's degree or higher. The median income was \$28,553 in 2000. In 2000 the average monthly benefit paid to retired workers was \$640.

The primary economic engine of the islands is tourism. It accounts for more than 70% of gross domestic product. Approximately 32% of the employed were in retail sales or the services provided for recreation, motels, hotels and restaurants. Manufacturing includes textile, electronics, pharmaceutics and watch assembly.

The total labor force is estimated to be 48,000 distributed among services (62%), industry (20%), agriculture (1%), and other (17%). The unemployment rate was estimated to be 6.2% in 1994.

In 1989 hurricane Hugo caused \$500 million damage from which residents have not yet completely recovered and which extended to the tourism industry. Local business owners continue to lament the drop in available advertising money that is funded through hotel taxes since many hotels had to close because of hurricane damage. In 1997 it was anticipated that only \$8.5 million would be raised through the hotel tax which was considered to be insufficient. The inventory of hotel rooms before the hurricane was estimated to be 1,400 while in 1997 was approximately 850. Governmental fiscal administration was

hampered by an imbalance in funds received compared to funds to be disbursed to vendors, tax refunds, and overdue wages.

One of the world's largest petroleum refineries is on St. Croix. Little agriculture is present and most foodstuffs are imported.

The Virgin Islands have a strategic importance located along the Anegada Passage which is a key shipping lane for the Panama Canal. Saint Thomas has one of the best natural deepwater harbors in the Caribbean.

The Islands have unique waste disposal problems. The U.S. Army Corps of Engineers conducted an environmental assessment at a St. Thomas landfill in 1996 and found that mercury vapors and phosphogenes were present which, after long term exposure, can produce illness and certain forms of cancer. Alternative solutions are being explored.

(Puerto Rico and the Virgin Islands are not included in all tables of the various reports utilized to describe these areas, which limits some comparisons to national published data.)

### RENAL DISEASE: PUERTO RICO AND U.S. VIRGIN ISLANDS

The number of newly diagnosed ESRD cases, inclusive of those who started treatment in out-of-area facilities, was 1,267 a 5% increase from 2001. Sixty-two percent of the newly diagnosed were reported to have a primary diagnosis of diabetic nephropathy. This continued to parallel the national trend of the growing number of diabetics starting dialytic therapy and represents a marked increase from 1990 when diabetes as the primary cause in new cases was only 45%. Hypertension was the second highest reported diagnosis at 15% and 8% of the newly diagnosed caseload was reported with a diagnosis of glomerulonephritis.

These rates vary when analyzing the data received on all prevalent consumers alive at year-end 2002 on the islands. Of the 3,502 consumers receiving treatment at year-end-- a 3% increase from 2001-- 52% reported diabetes as primary cause of renal failure, 16% glomerulonephritis and 17% hypertensive disease. The majority of consumers were reported as racially mixed (64%), male (63%). Age grouping is similar for both new cases and the prevalent dialysis patient population on the islands. Consumers in the 50-69 age group are the dominant population; 48% and 54%, respectively, in the incident and prevalent figures. Thirty-two percent of prevalent cases are between the ages of 30 and 54. Twenty-nine percent of the incident cases are age 70 or more. Twenty-one percent of the prevalent cases are age seventy or older.

The primary cause of death for ESRD consumers treated in Puerto Rico and the Virgin Islands at year-end was cardiac (36%); infection ranked second (32%).

## TREATMENT MODALITIES

Thirty-eight facilities were approved on the island of Puerto Rico to provide ESRD services and two facilities within the U.S. Virgin Islands (one hospital-based unit on the island of St. Thomas and one hospital-based unit on St. Croix.) Twenty-five facilities on Puerto Rico are freestanding clinics. There is one veterans administration hospital and 9 hospital-based units on Puerto Rico. The station count increased to 717 from 659 in 2001 (inclusive of Puerto Rico and the Virgin Islands). The two facilities on the Virgin Islands had a total of 20 stations and a total of 136 cases at year-end.

Treatment choice continued to favor staff-assisted hemodialysis-- 2,940 (87%) consumers in Puerto Rico and all consumers on St. Thomas and St. Croix. Self-care training in CAPD, CCPD and home hemodialysis were provided in Puerto Rico in spite of limited housing conditions. Seventy-nine percent of

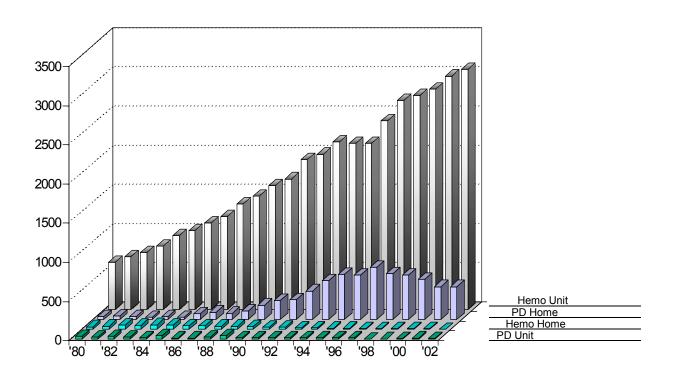
the home population was on home CCPD. In 2002, 338 consumers were on CCPD and 81 consumers were on CAPD. No consumers used home hemodialysis. The combined total of consumers on various forms of home dialysis in Puerto Rico equaled 426 in 2002, 521 in 2000, 574 in 1999 and 679 in 1998. No home consumers were reported on either St. Thomas or St. Croix.

Sixty-eight transplants were performed in 2002 at the one Medicare-approved transplant center. This was an decrease of 25% below 2001 performance (91). Of these procedures, 42 were from cadaveric donors. There were 354 consumers are on an active waiting list.

Formerly, the organ procurement agency was located at the transplant hospital and was part of that organization. In 1996 a separate agency was established, Life Link of Puerto Rico, which is affiliated with Life Link of Florida.

# Dialysis Modality/Setting Distribution: Puerto Rico/U.S.V.I. 1980-2002

**CASES** 



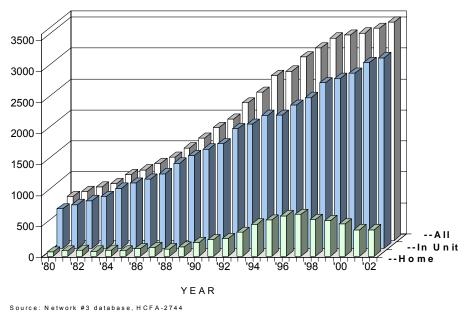
YEAR

Source: ESRD MIS ESRD Facility Survey, HCFA-2744

Trans-Atlantic Renal Council

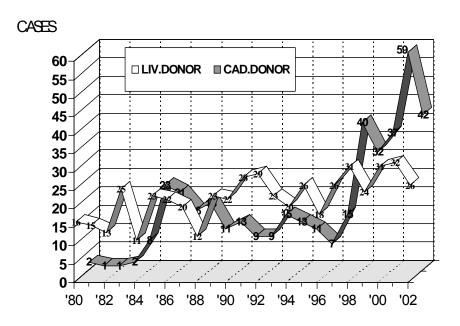
# Setting Distribution of Dialysis Cases Puerto Rico/U.S.V.I. 1980-2002

CASES



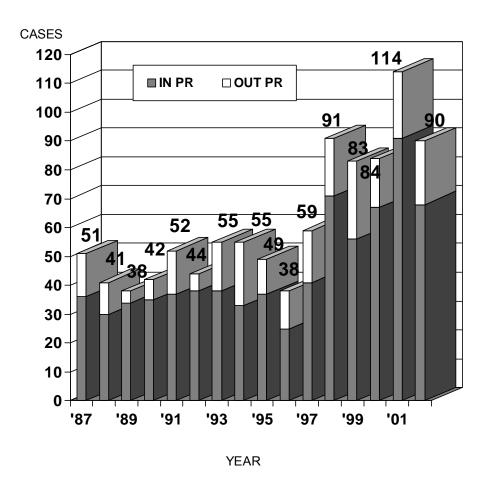
Trans-Atlantic Renal Council

# Renal Transplants Performed in Puerto Rico/U.S.V.I. by Type: 1980-2002



Source: Network #3 database, HCFA-2744 Trans-Atlantic Renal Council

# Total Puerto Rico/U.S.V.I. Residents Transplanted and Number Done in and out of Puerto Rico



Source: Network database; UNOS data 1994 forward; ESRD MIS ESRD Facility Survey

Trans-Atlantic Renal Council

### **B. NETWORK STRUCTURE**

#### 1. STAFFING

Professional and clerical staff conducted daily activities of the network organization under the direction of the Board of Trustees and in accordance with federal guidance.

The project director was Joan Solanchick, who administered the contract, maintained external relations through ongoing communication with other agencies, state programs and the general public, and supervised daily operations.

Jeanne Lavin, RN, joined the staff as quality improvement administrator from a hospital background and many years of experience in ESRD patient care. She monitors all quality improvement efforts, plans future project implementation and works with individual facilities.

Michele Inglese, RN, continued as senior quality improvement coordinator with quality improvement coordinators June Chronic-Huhn, RN, and Anna Marie Pellicano, RN. In these positions they assisted with the conduct of improvement activities, monitored facilities, performed on-site visits, clinical data review and responded to consumer problems.

Chris Brown and Mitch Parker developed data analysis and statistical reports. They assured computer support operations, validation, testing and design of special programs that implemented federal directives. Additionally, they trained facilities in the use of new federal Vision use and implementation.

Accurate data analysis is based on careful processing, manual review and data entry. Angie Sluck reviewed all MIS forms for completeness and accuracy prior to data input and obtained missing information. Cheryl Brown performed data entry, resolved discrepant reporting, monitored the accuracy and completeness of the database.

Tricia Phulchand joined the staff and monitored all project submissions as well as assisted in the implementation of facility transmission of Vision data.

Walter Stern was responsible for producing agency reports and designing complex layouts with computer imagery.

These individuals provided the clinical and administrative expertise to assure reliability of statistical data and oversight of quality improvement activities.

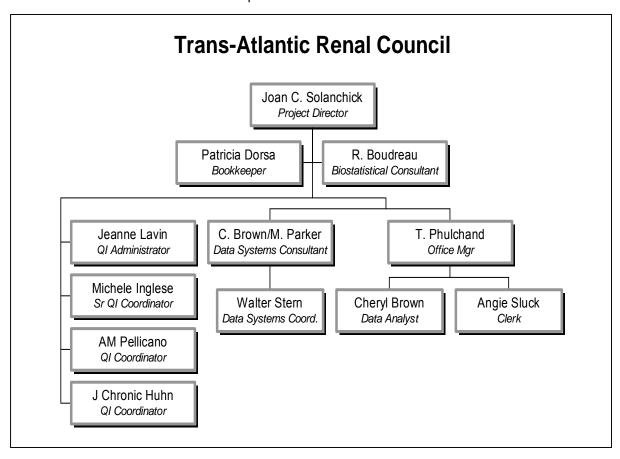
### **OPERATIONS**

There are two major functions within the operation of the network: quality improvement and data management. It could be maintained that quality improvement is the sole function of the network and data analysis serves only to focus and measure the quality improvement function.

Quality improvement personnel were responsible for staffing the Medical Review Board and all related activities, the federal clinical performance measures project, local quality improvement activities and educational programming. Staff prepared draft material for review by the Medical Review Board, monitored developments in the field, reviewed reports submitted by each facility and analyzed comparative results. Facility site visits were conducted when appropriate.

Data management personnel were responsible for all data input, report production, generation of diskettes and transmission of data to CMS. They subjected data to tests of statistical significance and interpreted results for clinical personnel as well as assisted in designing studies and producing reports.

Clerical personnel prepared documents, correspondence and general mailings as well as maintained files in a manner consistent with usual office practice.



Network staff conducted the ongoing collection and processing of data, review of compliance with federal requirements as well as network goals and objectives, and distribution of pertinent information to all ESRD facilities within the defined geographic region.

The Council of member facilities provided the direction for monitoring performance outcomes and measuring the quality and appropriateness of care. The Medical Review Board and the Board of Trustees provided invaluable advice and expertise to achieve improvements in patient care. In addition, a resource pool of knowledgeable ESRD consumers and other highly skilled clinical nephrology professionals (physicians, registered nurses, social workers, and dietitians) was developed to act in a consulting role for periodic review of educational materials, special studies, core indicators and speakers at educational meetings.

This "resource pool" has been valuable in assisting staff to "test" new data requirements and changes in quality improvement activities, and to analyze the impact of advancing technology or areas of interest. All board and committee members serve voluntarily with no compensation.

### 2. COMMITTEES

### **NETWORK COUNCIL**

The Council provided broad direction and guidance in the development of goals for self-care, transplant referrals and criteria selection for monitoring performance of providers and plans for improvement. Representation on the Council was multidisciplinary, culled from professionals with demonstrated expertise in their specific field and representative of the geographic characteristics of the network.

The Trans-Atlantic Renal Council ('Council') was composed of thirty-three (33) regular members: twenty-three (23) from New Jersey, seven (7) from Puerto Rico/Virgin Islands, and three (3) consumers. The formal Council representatives reflect the geographic area encompassed by the network as well as the various disciplines and types of facilities contained within the network stipulated by federal regulations. All Council members were selected from volunteers and approved by the Board of Trustees. Liaison members from governmental and voluntary agencies affiliated with the care of ESRD consumers were invited. To the extent possible, Council membership was restricted to not more than one person from a facility or affiliated group of facilities. Council meetings are open and a significant number of the renal community attends the annual meeting.

The geographic representation by discipline is illustrated below:

North	Central	South	Puerto
NJ	NJ	NJ	Rico
1 consumer	2 consumer		
5 physicians	3 physicians	2 physicians	2 physicians
3 registered nurses	1 registered nurse	2 registered nurses	2 registered nurses
1 social worker			
2 administrator registered nurses	1 administrator		
1 transplant physician			
		1 dietitian	

Council formal representation by type of facility follows:

	New Jersey	Puerto Rico
Hospital-based	12	1
Non-profit satellite	2	
Corporate provider	8	7

The Council met one time as allowed under contract. This meeting was used to present comparative data on local and national goals and provide educational programming on new technology and areas of interest. The meeting was held on November 6, 2002 at the Sheraton Woodbridge Place, in Iselin, New Jersey. Lecture topics and speakers were:

Network Activities

Bruce Zakheim, MD, President, Board of Trustees

Encouraging Home Dialysis: Peritoneal Dialysis

Glenn DuBov, MD Kathy Searson, BS, RN, CNN DCI North Brunswick Home Program Home Hemodialysis DeniseVanValkenburgh,BA,RN,CNN

Fresenius Medical Care

The Patients Who Try Our Patience Arlene Sukolsky

Executive Director, Network 17

An annual meeting highlight was the presentation by Barbara Ahmet Simon, BSN, of the Ahmet B. Ahmet Award to one consumers selected from the many inspirational nominations submitted by facility staff.

Fourteen posters prepared by New Jersey facilities were displayed at the annual meeting.

Anna North Jersey Chapter Validating Your Professionalism: The

Nephrology Nursing Certification

**Process** 

DCI North Brunswick Dialysis Center There is No Place Like Home

DCI North Brunswick Dialysis Center Adequacy
DCI North Brunswick Dialysis Center Immunizations

Ocean Renal Associates Role of the Nephrology Advanced

Practice Nurse

FMC Irvington Compare Your Intake and Visualize

Your Limits

FMC New Jersey Clinics Reducing Parathyroid Hormone Levels

in Fresenius Medical Care NJ Patients

FMC Union(Hillside) Monthly Patient Education

Hackensack University Medical Center Falls Prevention in the Out Patient

Dialysis Setting

Lillian Booth Dialysis Center Renal Rehabilitation in the Older

Population Through Travel

Our Lady of Lourdes Improving Errors Through Medication

**Error Reduction** 

Robert Wood Johnson University Hospital

Silver Care Center

Neonatal Hemodialysis New In-House Unit for Long Term Care

Residents and Acute Rehabilitation

**Patients** 

St. Joseph's Hospital Outpatient Dialysis Multicultural Approach for Patient Center

Education

### MEDICAL REVIEW BOARD

The Medical Review Board (MRB) evaluates the appropriateness of ESRD care, treatment procedures, and services delivered to ESRD consumers. The prescribed composition of the MRB is:(13) members and a chairperson from the following categories: a minimum of one physician board-certified in nephrology, an experienced nephrology registered nurse responsible for nursing services, a licensed renal social worker, a registered renal dietitian and a patient representative. All of the members are engaged in ESRD treatment.

The 2002 Medical Review Board was composed of two consumers, one registered dietitian, one social worker, four registered nurses and six physicians. Three members were from Puerto Rico and the remainder were from New Jersey. The following chart illustrates the MRB's composition:

Type of Facility	North NJ	Central NJ	South NJ	Puerto Rico
Hospital-based	1 physicians 1 social worker		1 nurse	
Non-profit satellite		1 physician	1 nurse	1 nurse (transplant agency)
Corporate provider			3 physicians 1 dietitian	1 physician 1 nurse
Patient	1 patient	1 patient		

The Board of Trustees accepted nominees for election to the Medical Review Board from the active organizational members. An individual must possess the qualifications and have demonstrated their ability to evaluate the quality and appropriateness of care delivered to ESRD to serve on the Medical Review Board.

The MRB has the responsibility for the development of criteria and standards for evaluation of care; review of facility protocols for patient modality selection; review of patient grievances as necessary according to standard procedures adopted by the Board; development of protocols for individual case review; evaluation of existing available services and recommendations for the addition of alternative services as needed; the analysis of facilities' compliance with network goals and recommendations for improvement.

No person serving on the MRB may have responsibility for review of any case in which he/she has, or had, any professional involvement, received reimbursement or supplied goods. No person serving on the MRB with a financial interest, direct or indirect, in a facility furnishing ESRD services may review the ESRD services of that facility. Confidentiality assurances are utilized by the MRB to protect the rights of consumers, providers, and facilities.

The MRB meeting dates and locations were:

March 6, 2002 Forsgate (Jamesburg, NJ)
June 5, 2002 telephone conference call
September 4, 2002 Forsgate (Jamesburg, NJ)
telephone conference call

### **BOARD OF TRUSTEES**

The Board of Trustees ('Board') consisted of eleven (11) members. Upon resignation of a member, inability to complete a term of office, or non-attendance at two (2) consecutive board meetings, the position would be deemed vacant and would be filled by a new member selected by the president of the board. The new member then would serve for the unexpired term held by the member whose position he/she filled.

The board elected from among its membership the following officers: president, vice president, secretary, and treasurer. The president served as the president of the board and chairman of the Council, and monitored all network operations with the project director. The vice president presided or acted in the absence of the president. The secretary was responsible for keeping minutes of all board meetings and assured proper maintenance of all records and reports (except financial) for the Council. The treasurer was responsible for reporting the financial status and budget preparation of the Council.

The 2001 Board of Trustees was composed of one consumer, two dietitians, three nurses and five physicians. One member was from Puerto Rico and the remainder were from New Jersey. The chart below illustrates the Board's composition:

Type of Facility	North NJ	Central NJ	South NJ	Puerto Rico
Hospital-based	2 nurse	1 physician	1 nurse	
Non-profit satellite	1 physician		1 dietitian	
Corporate provider		1 physician 1 dietitian	1 physician	1 physician
Patient		1 patient		

The election of officers took place at a regularly scheduled meeting of the Board. Election of officers was by simple majority of those members present and voting.

The board monitored and directed the daily operation of the network organization. The board has the authority to:

- Employ and terminate any personnel required for the business of the network;
- Prepare a plan which defines network goals, objectives and implementation of objectives;
- Prepare an evaluation methodology to measure progress;
- Develop network operating and governing policies and procedures;
- Suggest alternative approaches to meeting goals and objectives for the network's consideration;
- Review and update the network plan on a regular basis;
- Review all fiscal matters of the network and review records on such matters which include, but are not limited to, the collection and disbursement of all funds;
- Certify the representatives for appointment to the Council, and keep up-to-date records of the membership of the Council;
- Appoint members and designated alternates to the Medical Review Board; and
- Review the By-Laws, amending them when necessary.

To further assure a broad perspective on appropriateness of care and outcome measurements, a transplant surgeon and board certified pediatric nephrologist may serve on the board or as a consultant to the board. These members are selected based on their expertise to further promote the goals and objectives of the network.

The Board of Trustees meeting dates and locations were March 13, 2002 - Forsgate (Jamesburg, NJ) June 19, 2002 - telephone conference call September 18, 2002 - Forsgate (Jamesburg, NJ) December 11, 2002 - telephone conference call

### **DATA SYSTEM IMPLEMENTATION COMMITTEE**

This committee was formed in order to discharge the network's responsibility to assist facilities provide efficient care by utilizing current technology. The TARC web site was developed and maintained to educate consumers and the public, and translated into Spanish for the Hispanic communities of New Jersey and Puerto Rico.

During 2002, the Spanish Consumer web site was revised and updated, and the Question and Answer section was developed and made available on the web in July, 2002. The Internet Disclaimer, the

Treatment Locations sections, and the web links were reviewed and revised for both English and Spanish web sites. The Data Committee is presently in the process of developing a professionals web site for dieticians, nurses, physicians, technicians, and social workers.

The Data System Implementation Committee was composed of five nurses, one social worker, two dietitians, and three technicians. The chart below illustrates the Board's composition:

Type of Facility	North NJ	Central NJ	South NJ
Hospital-based	2 nurses 2 technicians		1 nurse
Non-profit satellite		1 technician	
Corporate provider	1 dietitian	1 dietitian 2 nurses	1 social worker

### 3. CMS NATIONAL GOALS AND NETWORK ACTIVITIES

### Improving the quality of health care services and quality of life for ESRD beneficiaries

TARC staff, Medical Review Board, Board of Trustees and the network Council developed goals and activities for a three year span, 2000 -2003. The goals are used to focus attention on and promote action in specific areas of nephrology to enhance the delivery of health care services. Renal transplantation and home dialysis often improve the quality of life for either newly-diagnosed or prevalent ESRD beneficiaries. TARC's transplant, home dialysis, and consumer education goal statements addressed the priority of access to information related to these renal replacement therapies as well as information on preventive health care and other related educational materials. A knowledgeable consumer involved in decision making related to their care contributes to their overall well being.

### TRANSPLANTATION GOAL

Promote patient access to kidney transplantation as a treatment choice through active support of patient education, assessment, and organ procurement. This goal was met.

- Activity: Dialysis facility transplant designees will track and report activity changes to TARC.
- □ Activity: After application of the transplant center's exclusion criteria, 100% of the network-wide caseload will be referred for a transplant evaluation within one year of beginning a regular course of dialysis.
- □ Activity: Within 60 days of being contacted, transplant centers will arrange for a transplantation evaluation appointment for 100% of the consumers referred to them.

TARC through its development and operationalization of transplantation goals promoted the option of renal transplant for suitable consumers. These efforts addressed the patient's desire for transplantation and its health advantages. Clinical and administrative leadership in hospital-based dialysis centers recognized the need for these organs and the benefits of transplantation for suitable ESRD consumers. The managers of the hospital-based dialysis facilities were encouraged during 2002 to increase hospital-wide awareness of organ procurement. Chief executive officers were asked to be receptive to organ procurement organization efforts for donor identification. Organ availability was beyond the scope of TARC activities and was under the direction of the organ procurement organizations (OPOs).

Dialysis programs were asked to track referrals of both newly-diagnosed and prevalent dialysis consumers for transplant work-ups. Reporting of this information will be done via a web-site which was still in the process of being developed in 2002. The facilities reported 2896 patients referred for a transplant in 2002. This monitoring would enable the Medical Review Board and Board of Trustees to assess whether consumers are being offered transplantation as a modality option.

To enhance identification of transplant candidates in 2002, the transplant centers of Saint Barnabas Medical Center and Auxilio Mutuo Hospital conducted transplant surgeon designee training programs for nurses. The programs offered initial training and a yearly review to keep the transplant designee nurses well versed in the latest information and how to apply clinical and diagnostic criteria to identify appropriate candidates and disseminate information about transplantation to patients and their families. The Saint Barnabas Medical Center's certification and recertification programs provided education for 233 staff members of federally approved New Jersey dialysis facilities and attendees from other agencies and states.

Long organ waiting lists are problematic both in network three and throughout the country. This long wait is further exacerbated for consumers with certain tissue matching needs. The network's six transplant facilities had 2,480 people on their kidney transplant waiting list as of December 31, 2002. This list is not comprised solely of consumers within the network boundaries.

Network three had six Medicare-certified renal transplantation programs operating during 2002, five in New Jersey and one in Puerto Rico.

- Auxilio Mutuo Hospital
- Hackensack Medical Center
- Newark Beth Israel Medical Center
- Our Lady of Lourdes Medical Center
- Robert Wood Johnson University Hospital
- Saint Barnabas Medical Center.

During 2002, these centers performed 431 kidney transplants.

The individual dialysis facilities within the network area reported 398 of their patients received transplant during 2002.

Many factors affected the actual number of kidney transplants performed: availability of transplant surgeons, operating rooms, intensive care facilities, specialized nurses and other ancillary staff.

According to the ESRD Annual Facility Survey (CMS-2744), 398 dialysis consumers (New Jersey: 331; Puerto Rico:64; US Virgin Islands:3) received a kidney transplant during 2002. Interstate transplant referral patterns have been operative for many years. Dialysis consumers sought transplant services not only at one of the six local programs but also at those in neighboring or affiliated states. For example, some New Jersey dialysis consumers received cadaveric organs or transplant work-ups in New York, Maryland and Pennsylvania during 2002.

A number of Puerto Rico consumers received kidney transplants in Texas, Massachusetts and Florida. While the six transplant programs provide convenient and state-of-the-art transplant services, the ultimate goal is for consumers to have choices among high-quality renal replacement therapies whether or not those services are located within the network's boundaries.

The vast majority (87%) of the Medicare-approved and Veterans Administration dialysis programs in New Jersey at year's end had a minimum of one patient receiving a kidney transplant in 2002 (Facilities had to be in operation for at least nine months and have an ambulatory dialysis caseload to be included in the calculation.) The range in number of dialysis consumers who received a transplant from those dialysis facilities was from one to eighteen consumers.

The dialysis facilities in Puerto Rico and the United States Virgin Islands, we also very active in sending their patients for transplant. 83% of their dialysis facilities (facilities had to be in operation for at least nine months and have an ambulatory dialysis caseload to be included in the calculation) had at least one of their dialysis consumers transplanted during the year. The range of recipients was from one to seven from any single facility.

The number of renal transplants performed yearly may be seen in the following chart:

TRANSPLANT CENTER	1994	1995	1996	1997	1998	1999	2000	2001	2002
Auxilio Mutuo Hospital	33	37	25	41	71	56	68	91	68
Hackensack Univ MC *	0	0	0	0	0	20	41	52	41
Newark Beth Israel MC	49	50	46	51	43	50	47	40	27
Our Lady of Lourdes Hospital	21	43	34	43	33	56	63	53	40
Robert W Johnson Univ. MC*	0	0	0	0	0	26	57	72	70
Saint Barnabas MC	<u>108</u>	106	145	<u>154</u>	<u>167</u>	<u> 181</u>	<u>171</u>	<u>169</u>	<u>185</u>
New Jersey subtotal	178	196	225	248	243	333	379	386	363
Total	211	233	250	289	314	389	447	477	431

<sup>\*</sup>Transplant service initiated in 1999

The number of kidney transplants decreased this year.

### Analysis of the transplant goal and its impact on the ESRD population

Network transplantation goals achieved positive results during 2002. Consumers on dialysis were reviewed for preliminary medical suitability according to medical criteria developed by the transplant programs. They received information from specially trained transplant surgeon designee nurses. Two thousand eight hundred ninety six (2896) consumers were formally referred to transplant surgeons for evaluation, an increase of 10% over 2001. By region, the number of consumers referred for a transplant work-up were: New Jersey, 2,238; Puerto Rico, 648; and US Virgin Islands, 10. Virtually all facilities that have an ambulatory caseload have a transplant referral procedure in place.

The number of dialysis consumers actually listed for a cadaveric transplant and on the waiting list at the end of 2002 was 2,137, a 10% increase from 2001. This number included people referred in prior years.

ESRD facility reports stated they: (1) had established or updated relationships with local organ procurement organizations, (2) participated in educational programs to increase awareness/acceptance of organ donation and cooperated with the educational efforts of the local organ procurement agency, and (3) reviewed and updated as necessary their internal policies for organ recovery. All hospital-based programs that maintain an ambulatory caseload reviewed their policies for organ retrieval and had inservice programs on organ retrieval.

The focus for the future will be establishing data entry functionality via the TARC web site. This will enhance the communication of patient status related to transplantation referral and allow process evaluation.

### CONSUMER EDUCATION GOAL

Promote consumer education to enable informed decision-making about therapy, participation in care, and enjoyment of improved outcomes.

□ Activity: Each dialysis facility will assure that at least one nursing member of its renal team is currently certified as a transplant designee. This certification is to be renewed annually by a renal transplant center based on recent designee training including clinically based inclusion and exclusion criteria used by the transplant team.

- Activity: Each facility will include information on home dialysis to all new cases and annually thereafter.
- Activity: Each facility will post, in a prominent place, a list of advantages of home dialysis or other positive material about home dialysis as a treatment option.
- □ Activity: Each facility will be encouraged to educate consumers about the value of vaccinations and screening programs in the prevention or early detection of illnesses.
- □ Activity: Each facility will be encouraged to develop a means to offer and track Hepatitis B, influenza, and pneumococcal vaccinations given to their consumers.
- □ Activity: Each facility will distribute to all consumers the educational material provided by TARC via electronic transmission or paper copies.
- □ Activity: Each facility will participate in the development of facility performance data to be made widely available to consumers.

At year's end, 233 registered nurses were educated to serve as transplant designees in New Jersey, 35 in Puerto Rico and 1 in the U. S. Virgin Island facilities. After excluding New Jersey facilities that became Medicare-certified at the end of the year and those dialysis units in Puerto Rico that do not maintain an ongoing caseload, 98% of the remaining units had at least one designee. The range per facility was one to eight. The two New Jersey facilities that did not have a certified transplant designee, one facility is a transplant center where the transplant coordinators maintain the transplant referral system, and the other facility has a transplant surgeon review and refer patients for transplantation. The newly approved dialysis programs within the network area were given information about the need to send a nurse assigned for transplant screening to the next available program offered.

The transplant designees serve as the initial link between the consumer and the ultimate goal of transplantation. Their responsibilities include: educating the dialysis patients about transplantation, reviewing cases for medical suitability, reporting referrals to the transplant surgeons and documentation of transplant discussions in the medical record. Dialysis providers, by pursuing this activity, sought to make the option of a transplant work-up available to medically-suitable consumers. Unfortunately during 2002, the number of organs available and suitable for use were still fewer than those needed or desired by network dialysis consumers.

2000-2003 goals were developed to include two new activities aimed at increasing consumer awareness about all modalities of care. Home dialysis was the focus of these activities. The first activity required all facilities to provide information about home dialysis to all newly diagnosed ESRD patients and annually to all existing patients.

The second activity required facilities to post information about the benefits and advantages of home dialysis as a treatment option in a prominent location in the facility.

Network-wide there were eighty-one facilities approved to provide home dialysis training, 55 in New Jersey and 26 in Puerto Rico and the U.S. Virgin Islands.

Three hundred fifty three patients in New Jersey facilities and two hundred thirty five patients in Puerto Rico were home trained in 2002 a 10% increase from 2001. Ninety three of the facilities had posted information on the advantages of home dialysis as a treatment option and one hundred twenty four, 95% of the dialysis facilities, provided information on home dialysis to all the newly diagnosed patients.

Facilities that do not provide home training services were asked if there was a mechanism in place to provide referrals to facilities that provide training for home dialysis for patients who are interested in home

dialysis. Fifty eight facilities or 92% of the non-home training facilities provide referrals for home training. A total of one hundred twenty four patients were referred to facilities that provide home training, a 20% increase from 2001.

One hundred twenty-eight (95%) of the facilities had a procedure for the distribution of educational material provided by TARC, to all consumers (including home-based consumers) and 95% of the facilities were able to provide information on all treatment modalities to all patients on an annual basis.

One hundred seven facilities (80%) have an identified resource to discuss all treatment and modality options with consumers. TARC will continue to focus on methods to increase the number of facilities that have a resource person who is capable of, and responsible for, informing consumers about the home modalities.

■ The 2000-2003 goals encourage facilities to educate consumers about the value of vaccinations and screening programs to prevent or detect illnesses. Facilities were also encouraged to develop a means to offer and track Hepatitis B, influenza, and pneumococcal vaccinations given to their consumers. One hundred twenty six (96%) of the facilities provided structured, educational information to consumers about the value of vaccinations and screening programs for the prevention or early detection of disease.

Posters, both in English and Spanish, highlighting the importance of receiving the flu vaccine were sent to all network 3 facilities. All facilities were provided a supply of brochures about the influenza vaccine for distribution to their consumers.

The 2002 Centers for Disease Control and Prevention survey results showed the majority of facilities (96%) were aware of the Recommendations for Preventing Transmission of Infections Among Chronic Hemodialysis Patients published in 2001 by the Centers for Disease Control and Prevention. Changes to facility infection control practices as a result of reviewing these recommendations were made by 72 (50%) of the facilities.

## Analysis of the Consumer Education Goal and Its impact on the ESRD population

It is widely believed that an educated ESRD consumer, one who understands and participates in the planning of their care, has a superior outcomes and enjoys a healthier lifestyle. The 2000-2003 consumer education goal and activities were developed in an attempt to more widely promulgate this concept throughout the network 3 facilities.

Ninety-seven facilities, (98%) of network 3, had a minimum of one certified transplant designee in their unit to review criteria for each ESRD patient's potential as a transplant candidate, provide their patients with transplant education and discuss the transplant as a treatment option .

One hundred seven, (87%) of the facilities in network 3, had an identified resource person to discuss home dialysis with their consumers. This area will continue to be a focus for future improvement activities.

Information was provided to all facilities about the benefits of the influenza vaccine.

The TARC web site provides a wealth of information for ESRD consumers. The Q & A portion is frequently visited to both refer to previously answered questions and pose new questions.

TARC met their goal, to promote consumer education which enabled informed decision-making about therapy, participation in care and enjoyment of improved outcomes. TARC will expend an increased amount of time, attention, and resources for the remainder of the 2000-2003 time period to continue improvement of this goal.

### HOME DIALYSIS GOAL

Encourage the use of home dialysis when appropriate to increase the network's percentages for self-care modalities.

- Activity: If home dialysis is not directly available within a facility, referral arrangements will be utilized.
- Activity: 10% of the network-wide dialysis patient caseload will use home dialysis.
- Activity: Dialysis facilities not approved for home training and follow-up will designate a home dialysis resource person to discuss/review home treatment as a modality choice.
- □ Activity: To enhance patient awareness of home dialysis advantages, TARC will organize a formalized education program for home dialysis designees in facilities not approved to provide home training.

The home training benchmark for 2000-2003 was, 10% of the network-wide dialysis patient caseload would be dialyzing at home. Unfortunately TARC feel short of goal achievement with only 9% of the dialysis population was using a home modality at the close of 2002.

Several factors influenced home referrals including the opening of additional dialysis stations and facilities. Peritoneal dialysis (PD) adequacy has become better understood in the last few years and with understand it was discovered fewer consumers achieved adequacy of PD treatment after their residual renal function declined. Due to these findings many home PD consumers returned to staff-assisted hemodialysis.

Home dialysis training providers reported many barriers: the increase in age, living conditions, poor support systems, poor eyesight, reduced muscular strength, and lack of dexterity, prevent an increase in the number of ESRD consumers able to dialyze at home.

According to information reported on the CMS ESRD Facility Survey, as of December 31, 2002, the number of network consumers treated on a home modality (CAPD, CCPD or home hemodialysis) was 1,089. This represents a decrease of 10%. New Jersey had 663 home therapy consumers, a 7% representation of their dialysis census. Puerto Rico, 426 home consumers,13% representation of their dialysis census. Neither of the U. S. Virgin Island facilities is approved to train and follow home cases. Network-wide, 9% of the caseload was on home dialysis therapy.

Over the last several years a steady decline in home dialysis patient treatment has been noted nationally as well as in network 3. The percentage of patients on home dialysis has decreased from 20% to 9% over the last 7 years.

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Year	Percentage of Patients on Home Dialysis in Network 3
2002	9%
2001	9%
2000	10%
1999	12%
1998	14%
1997	16%
1996	18%
1995	20%

This pattern is of concern to TARC. Despite new means of home dialysis, such as nightly daily dialysis, the number and percentage of patients electing to dialyze at home has decreased. All but 1 facilities in New Jersey and 1 facility in Puerto Rico stated that home dialysis information was offered to all patients in 2002. Additionally, 75% of facilities in New Jersey and Puerto Rico reported that they post home dialysis information for consumers, while the US Virgin Island facilities did not post home dialysis information. The US Virgin Island facilities do not provide home dialysis training or support.

Providers reported 537 consumers completed a home dialysis training course for CAPD, CCPD and home hemodialysis. Three hundred thirty seven consumers were reported to have successfully completed some form of home training program during the year in New Jersey. By modality, the breakdown was CAPD:133, CCPD: 198 and hemodialysis: 6. Puerto Rico had an additional 200 consumers complete some type of home dialysis training: CAPD:28; and CCPD:144. Almost one hundred percent (99.6%) of facilities not providing home training had a mechanism in place to provide referrals to a provider of home training. One hundred twenty four patients were referred to facilities for home training by facilities that did not provide training.

All facilities with adult patients provide information on home dialysis to all newly diagnosed patients. All facilities provide information on all treatment options to all patients annually. A107 facilities had a staff member designated to discuss all treatment options with new patients. Educational material provided by TARC was distributed to consumers and 98% of facilities have a procedure for distributing educational materials to all consumers including home-based consumers.

### Analysis of the home dialysis goal and its impact on the ESRD population

Even though there are clinically valid reasons why the overall home dialysis percentage is not increasing, home treatment can be a good choice for some consumers. Chronic renal replacement therapies delivered through home treatment can afford the patient additional personal control resulting in a more independent lifestyle and an increase in activities. Each element assists the consumer in attaining a healthy emotional adjustment.

The use of daily hemodialysis as a viable treatment option was started in New Jersey on a very limited basis. Reimbursement issues have remained a barrier to the increase in use of daily hemodialysis Although the benefits are well recognized in the renal community a standardized nomenclature has not been established for this variation in treatment. Nationally, a few centers provide daily in-center treatment but most limit more frequent treatment to the home environment.

While a usual course of facility treatment includes dialysis three times each week for a period of 3.5-4.5 hours, daily dialysis usually will occur six nights for a period of six to eight hours. Monitoring of the daily (some may be nocturnal) treatments may be performed at a remote station. The patient's and machine's readings are monitored and when a significant variation is noted the patient/care partner is alerted. This topic was an area of focus at the 2002 TARC Annual Meeting.

Peritoneal home therapies during 2002 were again identified as the most successful modality for consumers who have been recently diagnosed with ESRD and also have residual renal function. Home dialysis for this population provides a transition into dialysis that is less restrictive on transportation and schedules. Although all the benefits are discussed and no clinical preclusions exist, some newly diagnosed consumers chose in-center care over home dialysis. The general consensus is that convenience and availability of nearby dialysis providers is a key variable in that choice.

TARC truly believes home dialysis would be beneficial for many of their consumers and continues to develop programs assist the consumer in making an educated decision for their health care. The development and inception of the home dialysis designee program is to insure the continued discussion and implementation of the goal activities specified above resulting in all the multidisciplinary renal teams to considering all modality choices when orienting newly diagnosed ESRD consumers.

### **VOCATIONAL REHABILITATION GOAL**

The goals encourage individualized patient care planning that addresses the attainment of the highest quality of life possible with emphasis on vocational rehabilitation, whenever appropriate was met.

- Activity: The network will make available on loan to both newly approved and existing facilities both text and slides from the Life Options Rehabilitative Advisory Council (LORAC) for use in staff in services and patient education.
- Activity: Each dialysis facility will complete at least annually the LORAC self-assessment tool to identify efforts in the five rehabilitative 'E's: encouragement, education, exercise, employment, and evaluation.
- **Activity**: Assure that facilities periodically evaluate their treatment scheduling practices or other facility policies which may act as disincentives to vocational rehabilitation.
- Activity: Each dialysis facility will compile the number of dialysis patients, ages 18-54, that were
  referred to the Vocational Rehabilitation Program, and the number of dialysis patients, ages 1854, employed (full or part time) and attending school (full or part time).
- Activity: The network will encourage the use of the SF-36 assessment form.

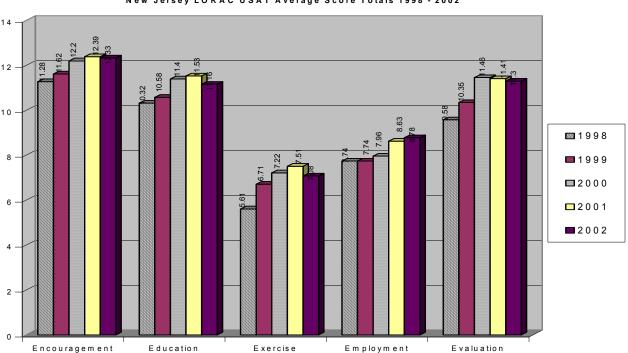
Even though kidney failure is not a curable disease, individuals can live very long and productive lives. Rehabilitating the patient with end-stage renal disease is admittedly difficult in certain situations. Improving outcomes of kidney disease usually requires that patients learn to manage their illness, report their symptoms accurately and advocate on their own behalf. TARC will continue to encourage patients to become more informed partners in their own care.

The concept of renal rehabilitation involves more than working to improve the clinical and functional status of dialysis patients. It is a comprehensive approach to care with the goal of helping patients resume productive activities and independent living (LORAC, 1997). As a way of measuring the progress at the facility level, TARC used resources developed by the Life Options Rehabilitation Advisory Council (LORAC) to focus unit planning, effort, and attention on rehabilitation. Training material and slides were made available for dialysis providers to use for facility in-service programs and program development. The LORAC "Catalog of Materials" as well as listings of the vocational rehabilitation office in New Jersey, Puerto Rico and the Virgin Islands were sent to each facility.

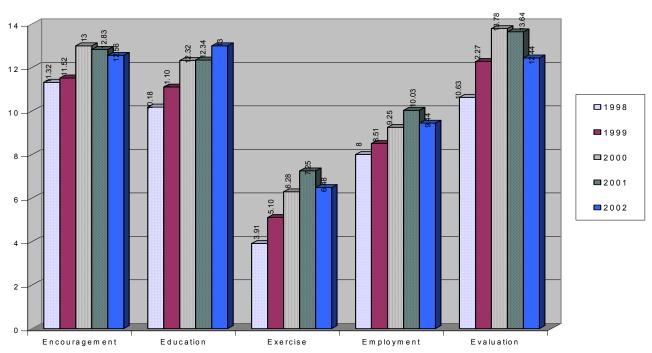
In the year 2002, even with the advent of several new dialysis facilities in New Jersey and Puerto Rico, there was a 90% response rate for the network facilities completion of the Unit Self-Assessment Tool (USAT). It is important for all facilities to remember that each year the USAT results build on the ones from the year before and contribute to establishing a continuous process of care with attention to improved outcomes for those with chronic kidney disease.

As can be seen through the efforts of the network and each facility, many dialysis facilities maintain activities with an active team approach to promote the Vocational Rehabilitation Program by:

- Using a centrally-located bulletin board that features stories or topics regarding rehabilitation;
- Assessing consumers' physical status, mental health, and general well-being on a regular basis;
- Assessment of patient, family, and staff attitudes toward rehabilitation;
- Informal screening for employment status or potential.
- Determination of ESRD consumers' job skills and suitability for vocational rehabilitation;
- Providing information about end-stage renal disease to employers as requested;
- Making information available about the benefits of working
- Informing consumers annually about treatment modalities to accommodate work and life interests:
- Utilizing the redesigned Life Options website (www.lifeoptions.org), which offers all Life Options print materials via the website allowed users to immediately obtain materials in unlimited quantities.
- Non-print materials from Life Options can now be ordered via the web at no cost to facilities. This includes videos, audios, posters and exercise binders.



New Jersey LORAC USAT Average Score Totals 1998 - 2002



Puerto Rico & U.S. Virgin Islands LORAC USAT Average Score Totals 1998-2002

Consumers can be motivated to learn more about kidney disease and its treatment so that they will become more involved in self-advocacy, self-management, and self-care. Helping consumers to set goals, share success stories, and support independence are examples of encouragement activities that can ultimately improve quality of life on dialysis. Consumers need to participate in decisions about their own care. In order to do this, they must first understand their disease and its treatment.

Educating consumers is the key to this understanding. To achieve positive outcomes educational goals must be geared to the needs and readiness of the consumer. Learning style and any barriers to learning, e.g., vision, hearing, or language problems must be addressed. Learning about kidney disease and all the treatment options can help consumers maintain a sense of control despite the challenges. It is critical to involve family members in educational efforts. Increased personal control, often gained through patient and family education, has been linked to improved adherence to treatment regimens and better quality of life.

TARC encouraged dialysis providers to discuss responses and results within their internal quality improvement programs and to make every effort to initiate at least one new rehabilitation-directed activity for the coming year. TARC promoted the concept that all renal replacement encounters are opportunities to enhance rehabilitative potential.

Patient teaching, communication about medication administration and diet, exercise, improved compliance with treatment schedules, maintaining or restarting employment or school attendance were all favored as means to enhance vocational and other rehabilitation scores. TARC encouraged patient care planning that would address attainment of the highest quality of life possible for each patient. By means

of goal statements and correspondence, emphasis was placed on vocational rehabilitation whenever appropriate.

## Analysis of the vocational rehabilitation goal and its impact on the ESRD population

Thirty-five of ninety-one dialysis units in New Jersey, and twenty-three of twenty-five dialysis units in the U.S. Virgin Islands and Puerto Rico reported that in-service programs or educational services on vocational rehabilitation were conducted in 2002. In New Jersey thirty-two of the ninety-one educational programs were conducted for patients, and in the U.S. Virgin Islands and Puerto Rico twenty-three of thirty-six sessions were conducted for patients. In Network # 3, fifty-eight (50%) of the dialysis facilities conducted in-service programs or educational services on vocational rehabilitation, and forty-eight (41%) utilized the SF-36 Health Status Survey form in their dialysis facilities in 2002.

The following information is the analysis of the Facility Survey Addendum question which requested information about vocational rehabilitation related programs, the numbers of employed patients, and the number of patients attending school. The dialysis units in New Jersey reported that one hundred twenty-one patients of the 18-54 age group in their dialysis caseload were referred to a vocational rehabilitation program. There were one thousand one New Jersey patients, age 18-54, employed (full or part time), and one hundred eighteen patients, age 18-54, attended school (full or part time). In Puerto Rico, one hundred thirteen patients of the 18-54 age group in their dialysis caseload were referred to a vocational rehabilitation program, and there were two hundred twenty-four patients, age 18-54, employed (full or part time), and twenty-five patients, age 18-54, attended school (full or part time). There were no patients in the U.S. Virgin Islands of the 18-54 age group referred to a vocational rehabilitation program. There were thirteen patients in the U.S. Virgin Islands patients, age 18-54, employed (full or part time), and two patients, age 18-54, attended school (full or part time).

One of the network's goal activities encouraged facilities to evaluate their treatment schedules as well as other facility policies that could be disincentives for working consumers or students. In the past, consumers at staff-assisted hemodialysis facilities had expressed problems with their dialysis schedules when they returned to work or school. Facilities reported that 52% of New Jersey facilities, 58% of Puerto Rico facilities and 50% of facilities in the US Virgin Islands offered a staff assisted hemodialysis shift after 5:00 p.m.

The goal to emphasize rehabilitation and individualized care planning was achieved in 2002. Vocational rehabilitation is an ongoing process that continually needs encouragement to continue it's development. There are still several areas that need improvement, and information along with expectations will be communicated to the dialysis facilities.

# ENCOURAGE FACILITIES TO DEVELOP CONTINUOUS QUALITY IMPROVEMENT SYSTEMS THAT UTILIZE CURRENT THEORIES

- □ Activity: Facilities will utilize the continuous quality improvement (CQI) resources provided on the TARC web site.
- Activity: Medical Directors will participate/ lead multidisciplinary CQI teams and involve all nephrologists granted facility privileges, in the institution of appropriate CQI methodology.
- Activity: Facility management will perform random quality reviews of facility's CQI systems and serve as a resource for further system development.
- □ Activity: TARC will perform random quality reviews of facilities CQI systems to assist local management in system development.
- Activity: Each facility will provide Web access and e-mail capability to each discipline on an ongoing basis.

 Activity: Encourage facilities to begin to develop an internal process to examine life-threatening medical errors.

#### Web Site

The Data Implementation Committee comprised of dietitians, nurses, dialysis technicians, an information technology coordinator, and a social worker met several times during the year to plan, organize, develop and evaluate the necessary components of the web site's professional section. The format was further developed and expanded to include but is not limited to the following categories: TARC information, reports, data, quality improvement, nephrology team, and resources.

A user-friendly, practical, and informative web site is being designed for nephrology professionals. The site will contain: information and appropriate links to facilitate information sharing, management of the dialysis environment, and provide resources useful in the daily practice of care.

The consumer section of the web site has been available for more than a year. Treatment locations section was reviewed and revised to include all new dialysis facilities, update the addresses, phone numbers, and services provided for each facility. Most recently, the site was translated into Spanish specifically for Puerto Rico.

The question & answer portion of the site allowed visitors to post ESRD related questions. A wide variety of questions in both English and Spanish were answered by Medical Review Board members. The breath of question topics spanned from the life span of an ESRD patient to assistance with locating a transplant unit.

#### Facility CQI

Facilities were asked if their facilities had CQI meetings at least quarterly. Only two facilities in NJ stated they did meet at least quarterly to discuss CQI. Two facilities in NJ stated the medical director did not participates on the CQI team. However, 15% of the facilities stated that the medical director does not promote the involvement of all attending nephrologists on CQI teams. 65% of the facilities stated they use the TARC website as a resource for quality improvement.

#### QI Site Visits

TARC staff performed four quality audits in New Jersey facilities. The quality audits were performed in response to consumer complaints and significant deficits in quality benchmarking indicators(quality indicator data was obtained from each unit's submission of their quarterly Hemodialysis Improvement Project). During each audit many areas of dialysis operations were reviewed and discussed, including policies, procedures, systems for monitoring clinical process, patient outcome measures, dialysis adequacy, anemia management, and technical issues. TARC staff made recommendations to assist in improving processes and systems at the close of each meeting. A written report of the findings during the audit was provided to medical directors and facility management. One facility demonstrated remarkable improvement within six months of the visit. TARC continues to closely monitor the remaining three facilities.

Ninety seven of New Jersey facilities, thirty one of the Puerto Rico facilities and all of the USVI facilities reported they had a process in place for the purpose of examining life-threatening medical errors, this resulted in a 98% rate for the Network.

## Analysis of the Continuous Quality Improvement Systems Goal

The current environment of health care is ever changing and to insure the proper delivery of care there needs to be complex systems in place. These systems must be continually reviewed and updated to meet the ever changing needs of the patients. The facilities in the network have developed and implemented various CQI systems to examine their present processes/systems and make necessary changes in response to this changing environment. Safety and reduction of medical error were topics on the forefront this year. The vast majority of facilities (98%) had a mechanism in place for examining life-threatening medical errors.

Facilities have CQI meeting regularly (a minimum of quarterly in which the medical director participate. One area the network views as problematic is the attending nephrologists' lack of involvement in the CQI process. At the time of this report TARC is unsure of the etiology, is it based on leadership/management issues or a lack of interest?

The TARC website made great strides in 2002 and was utilized by the facilities. During the year TARC and the facilities engaged in an interactive exchange of information via a secure web site to facilitate a quality improvement project. As with any new venture technical problems arose but has great expectations for future quality improvement projects.

## ENCOURAGE UTILIZATION OF RECENT SCIENTIFIC EVIDENCE TO IMPROVE PATIENT CARE

### Anemia Management

- □ Activity: Each facility will provide erythropoietin and intravenous iron replacement medications for supporting hemoglobin synthesis.
- □ Activity: Each facility will monitor iron status of all consumers and maintain ≥ 80% of the caseload with transferrin saturation levels > 20% and ferritin results > 200 ng/ml.
- □ Activity: At least 80% of the dialysis caseload will maintain a hemoglobin ≥ 11 Gm/dl.

The hemoglobin threshold established by TARC expected 80% of the dialysis caseload to maintain a hemoglobin level > 11gm/dl.

Percent of HD Patients with Hemoglobin Values > 11 Grams in 2002

Area	1 <sup>st</sup> Qtr	2 <sup>nd</sup> Qtr	3 <sup>rd</sup> Qtr	4 <sup>th</sup> Qtr
New Jersey	75.6%	76.4%	76.8%	78.1
Puerto Rico	66.8%	72.1%	73.6%	72.6
U.S. Virgin Islands	72.6%	73.8%	69.3%	70.3
Network	73.5%	75.3%	75.8%	76.6

In 2002 the Medical Review Board analyzed anemia management using hemoglobin values as well as transferrin and ferritin levels to assess the possible causes of lower values. TARC established expected achievement levels for certain iron indicators: transferrin saturation levels  $\geq$  20% and ferritin levels of  $\geq$  200 ng/ml. New Jersey facilities reported that 78% of consumers met the iron indicators established, 79% in Puerto Rico and 64% in the US Virgin Islands. All facilities reported that they routinely monitored the iron status of all consumers and that anemia/iron management is part of the internal CQI program. However, only 39% of facilities track blood transfusion administration.

Area	Percent of HD patients with Transferrin Saturations ≥ 20%	Percent of HD patients with Ferritin results ≥200ng/ml.
New Jersey	78.2%	85.6%
Puerto Rico	79.4%	79.6%
US Virgin Islands	64.6%	52.1%
Total	78.3%	83.8%

## **Nutrition**

□ Activity: Encourage facilities to monitor patient nutrition and evaluate the daily protein intake against the goal of 1.2 Gm/Kg/day with a caloric intake of about 30 to 35 Kcal/Kg/day.

Another activity categorized under the network goal to utilize recent scientific evidence to improve patient care was to encourage dialysis facilities to evaluate daily protein intake and offer counseling to consumers on low intake rather than focusing exclusively on serum albumins. Improving patient nutrition is also a means to enhance ESRD survival and to reduce morbidity. Ninety three (95%) New Jersey facilities reported evaluating daily protein intake of their consumers. In the islands, 92% of facilities evaluated daily protein intake as a means to determine counseling needs for consumers

Facilities also reported on a quarterly basis the number of patients that had albumin levels in identified quartiles. Facilities used both bromcresol purple and green methods to perform albumin level testing. The results for the year pr 2002 were as follows:

Nutritional Status: Percent of HD Patients with Albumin Values > 4.0 Gm/dL

Area	Quarter 1	Quarter 2	Quarter 3	Quarter 4
NJ	35.4%	36.6%	32.6%	34.2
PR	45.2%	44.8%	42.1%	45.9
USVI	16.6%	39.7%	19.7%	31.1
Network	37.6%	38.6%	34.8%	37.1

## **Dialysis Adequacy**

- Activity: Each peritoneal dialysis facility will include measurements of delivered dialysis in their internal CQI programs.
- Activity: Peritoneal dialysis facilities will measure delivered dose of treatment at least every four months.
- □ Activity: At least 80% of the peritoneal dialysis caseload will have Kt/Vs > 2.0.
- □ Activity: If not already doing so, hemodialysis facilities will quantify the delivered dose of hemodialysis in adult and pediatric consumers using formal urea kinetic modeling.
- □ Activity: Each hemodialysis facility will assure that all blood samples for blood urea nitrogen (BUN) measurement are drawn according to evidence-based clinical practice guidelines on all shifts and by all personnel.

□ Activity: At least 80% of the hemodialysis caseload will maintain a delivered dose of dialysis ≥ 1.3 Kt/V.

In 2002 forty-nine (49) New Jersey facilities and 23 Puerto Rico facilities offered home training and support for home peritoneal dialysis. (There are no peritoneal programs in the US Virgin Island facilities.) In New Jersey, 407 of 645 consumers (63%) had a Kt/V  $\geq$  2.0. Puerto Rico reported 208 of 419 consumers (49%) met this target. Network-wide this represents 58% of the consumers achieving goal attainment. Ninety-two percent of facilities that provide peritoneal dialysis statedthat measurements of delivered dose of treatment are performed at least every four months. All facilities include adequacy results in their CQI meetings.

To assess hemodialysis treatment adequacy some facilities were equipped to perform kinetic modeling but the network-wide effort to improve had to employ a measurement that would be used by all facilities. For that reason, adequate dialysis was defined as one in which the urea reduction ratio (URR) was at least 65%. Facilities were expected to internally monitor not only each patient's URR but to also be sure that the post dialysis blood urea nitrogen test results were not the result of an incorrectly drawn sample which was diluted with either saline or recirculated blood. All hemodialysis facilities reported that post dialysis blood samples of blood urea nitrogen were drawn according to evidence-based clinical practice guidelines. All facilities had available for their internal use a monthly distribution of the number and percentage of their hemodialysis patients who received various doses of dialysis.

The TARC Medical Review Board and Board of Trustees analyzed facility-specific dialysis dose profiles. Facility information was not coded so members could compare like facilities when analyzing data. Uncoded data for all facilities were sent to each dialysis unit to allow facilities to benchmark.

For those facilities that did not meet the goals, the medical directors of the facilities were contacted. Medical directors were asked to identify reasons for low performance and resolve them. Through data analysis, correspondence, telephone discussions with network staff, and unannounced facility site visits, the network assured that adequacy of dialysis became a component of internal facility quality review and action. Facilities were provided with basic quality improvement tools to assist them with the improvement process.

Percent of Hemodialysis Patients with URRs > 65% in 2002

Area	1 <sup>st</sup> Qtr	2 <sup>nd</sup> Qtr	3 <sup>rd</sup> Qtr	4 <sup>th</sup> Qtr
New Jersey	86.4%	87.2%	87.4%	87.8
Puerto Rico	82.1%	82.0%	82.0%	84.1
US Virgin Islands	87.3%	80.9%	82.5%	85.3
Network	85.3%	85.8%	85.9%	87%

New facilities were included in the adequacy of dialysis activities. Adequacy tracking materials were sent to them along with the goal statement that eighty percent of hemodialysis patients should receive a dose of delivered dialysis of at least sixty-five percent.

#### Vascular Access

- □ Activity: Hemodialysis facilities will work with local surgeons to increase the percentage of arteriovenous fistulae within the facility to ≥ 50%.
- Activity: All consumers with failed grafts will be reassessed for placement of a fistula.
- □ Activity: Hemodialysis facilities will work with local surgeons to decrease the percentage of catheters within the facility to < 15%

- □ Activity: Each hemodialysis facility will create/maintain a system to identify the type of vascular access of each patient, its location, date of creation and subsequent modifications
- □ Activity: All hemodialysis and peritoneal dialysis facilities will track and report access infections (defined by positive blood cultures) via the web site.

Within the context of the TARC goals, network facilities were encouraged to track life spans of their patients' vascular accesses. This was requested as a response to advice from the vascular access workgroup for the practice guidelines of the Dialysis Outcomes Quality Initiative. After evaluating available scientific data on hemodialysis vascular accesses, the work group concluded that patients' outcomes and quality of life could be significantly improved by increasing the placement of native arteriovenous fistulae as compared to grafts or catheters. The majority of facilities (82%) attempted to work with local vascular surgeons to increase fistulae placement. However, less than half (48%) of facilities tracked the longevity of hemodialysis vascular accesses.

Vascular access continues to be a considerable focus of QI activities. Infection related to catheter types were reviewed in 2002. The information the facilities provided is consistent with published literature and quite disturbing. The facilities were asked to provide the number of patients with positive blood cultures using various access types. Note, this is number of patients, not number of blood cultures or events. It is notable that 75% of the patients with positive blood cultures had catheters as an access for hemodialysis, which was consistent with the previous year. No improvement was noted in the infected catheter issue. It must be noted that the distribution of accesses changed slightly in 2002 so the number, not percent, of access-specific infections may vary. The facilities provided the following information:

	Number of patients with positive blood cultures by vascular access type		
	2001	2002	
AV Fistula	149	225	
AV Graft	347	374	
Catheters	1,514	1,833	
Other	31	2	
Total	2,041	2,434	

Additional goals were addressed in the assessment and reduction of catheters in hemodialysis quality improvement project.

## Analysis of the scientific evidence goal and its impact on the ESRD population

The goal to encourage utilization of the most recent scientific evidence to improve delivery of patient care was met.

Network facilities increased the number of patients and percentage of their caseloads that received a dose of delivered hemodialysis equivalent to at least a urea reduction ratio of 65%.

Network-wide 87% of 11,183 patients with reported adequacy measurements received the required minimum dose or greater, compared to 84.8% of 10,796 patients the prior year. In other words, dialysis dose improvement was documented for 574 hemodialysis patients. Through distribution of materials, data tracking and monitoring, facility feedback, correspondence and improvement plans, the goal to improve awareness and cooperation among ESRD facilities in addressing adequacy of dialysis was met and 87% of patients received an appropriate dose of treatment.

Results in anemia management were measured by tracking monthly hemoglobin values. The change in percentage of hemodialysis patients with hemoglobin levels of at least 11 gm/dl rose from 73.7% of 10,913 to 76.6% of 10,913 patients with hemoglobin results. Higher hemoglobin measurements were documented for 633 patients network-wide. During the year, 4,091newly diagnosed in-center patients entered the staff-assisted treatment system. With the considerable challenge of assessing, diagnosing, treating and sustaining clinically relevant anemia management in so many new cases, network providers achieved a net increase in the number and percentage of patients with adequate hemoglobin values. A significant improvement was noted whereby 76.6% of the patients had hemoglobin' levels of at least 11 gm/dl at year's end.

## Summary of Quality Improvement Projects

Through recent contracts with ESRD networks, the Centers for Medicare & Medicaid Services sought to improve medical care for Medicare beneficiaries who were end stage renal disease consumers. Areas of quality focus were identified from within the scientific nephrology community. That community identified intermediate outcomes, which were known to influence ESRD mortality and morbidity, including: dose of delivered hemodialysis expressed as a urea reduction ratio; serum albumin as a marker for a patient's nutritional status; pre-dialysis hematocrit and hemoglobin and vascular access for hemodialysis. In prior years CMS developed a core indicator / clinical performance measure and anemia project as a mechanism to profile national and regional progress in these indicators. In 2002, TARC completed the Hemodialysis Adequacy Prescription Quality Improvement Project (HAPQIP) and initiated the Assessment and Reduction of Catheters in Hemodialysis Quality Improvement Project (ARCHQIP).

## The Clinical Performance Measures Project

The 2002 ESRD Clinical Performance Measures project was the ninth year of such data collection in more than 2,000 dialysis programs nationwide. CMS characterized the project as a 'snap-shot' description of adult peritoneal and in-center hemodialysis patients. The effort focused on dose of delivered dialysis, anemia management, serum albumin values and vascular access. The samples included: 8,399 hemodialysis patients, 1,352 peritoneal patients, and 668 pediatric patients. Additionally, facility surveys were distributed to 5% of the approved facilities nationwide. The Veteran's Administration hospitals provided data on 100% of their population while all other facilities were subject to a scientifically selected sample number of study patients.

During the spring of 2002, the network office received project data collection forms and patient form labels. Network staff mailed one hundred seven data abstraction facility packages; 691 patients were involved. Instructions asked that clinical performance measures forms be submitted for only those incenter hemodialysis patients who received thrice-weekly treatment. For various reasons, 573 forms were completed.

Number of Network 3 Clinical Performance Measures Participants, 2001

	Dialysis Facilities	HD Patients	Pediatri c Patients	PD Patients	Total Patient forms
New Jersey	88	369	17	29	415
Puerto Rico/VI	29	120	7	31	158
Network	107	489	24	59	573

Upon receipt in the network office, the 573 data abstraction forms and 6 facility surveys about unit practices and procedures were checked for accuracy and reasonableness of information provided. All forms were entered and completed records were transmitted electronically to CMS.

CMS selected a 5% peritoneal dialysis sample for network validation and the network selected a 5% hemodialysis validation sample. Facility staff sent documents from 28 selected records to the TARC office for review. TARC staff identified any discrepancies, input changes and transmitted those records to CMS.

The 2002 ESRD Clinical Performance Measures Project Annual Report to medical directors, administrators and nursing managers of each facility. Facilities were encouraged to compare nationwide information with their local data and to examine their own patient care practices and processes. The network Medical Review Board and Board of Trustees used the information to identify progress over time and to compare the results of New Jersey, Puerto Rico, and the US Virgin Islands to other areas of the country.

The Medical Review Board discussed CMS's report and reviewed selected information with facilities at the annual Council meeting. For the country as a whole, eighty-nine percent of the sampled adult, incenter hemodialysis patients received a dose of dialysis equivalent to a delivered calculated, single session Kt/V ≥ 1.2. The percentage increased each year of the project. In network 3, eighty-eight percent of the sampled population received a dose of dialysis equivalent to a delivered calculated, single session Kt/V ≥ 1.2.

The CMS-designed Clinical Performance Measures report was designed to stimulate caregivers in dialysis facilities to ask questions such as: What percent of patients in our facility received the minimum adequate dose of hemodialvsis? If results were less than the national average or less than the threshold established by the Medical Review Board, then facility caregivers were to consider their differing results as an opportunity to improve care. Overall, the goal of the project was that, collectively, providers would achieve the following intermediate outcomes for adult, in-center hemodialysis patients: Urea reduction ratios of at least 65% (or a Kt/V of 1.2);

Serum albumin values of at least 4.0 gm/dl; and

Hemoglobin values of 11 – 12 gm/dl.

Anemia data were also analyzed. In the United States 76% of adult in-center hemodialysis patients had mean hemoglobin values of ≥11 gm/dL; in network 3 that percentage was 78%. This was a 5 % increase for network 3 from the previous year. The data were discussed with the Medical Review Board and Board of Trustees.

Nutritional status, measured by albumin levels, of hemodialysis patients was again assessed. There are 2 commonly used methods of albumin measurement, bromcresol green (BCG) and bromcresol purple (BCP), which have slightly different results. The network data showed 33% of patients had an albumin of ≥ 3.7gm/dL by BCP or 4.0 gm/dL by BCG. The United States had 37% of patients with those albumin levels.

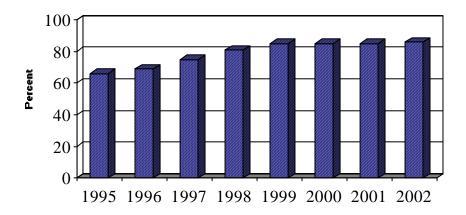
Vascular access CPM I states at least 50% of all new hemodialysis patients should have a primary arteriovenous fistula (AVF) as the primary access. It further states that 40% of all prevalent hemodialysis patients should have an AVF. According to the results of this project 32% of all hemodialysis patients in network 3 had an AVF, while, nationally, 31% of patients had AVFs. Both network 3 and the nation saw an increase in the percentage of patients with AVFs but there is a long way to go.

The federal peritoneal dialysis core indicator project is designed to assist providers to improve the care they deliver by highlighting opportunities for positive change. The patient sample resulted in national estimates only (not regional or network-specific).

During this year's project, clinical information was sought for October and December 2001 and January through April 2002 for hemoglobin levels, serum albumin, blood pressure and dose of delivered dialysis for peritoneal dialysis patients. Data were abstracted from 59 peritoneal dialysis patients medical records in network 3 facilities; nationwide, records for 1,352 adult peritoneal patients over the age of eighteen years were examined.

CMS found that dialysis adequacy measurements (weekly Kt/V urea or weekly creatinine clearance) were assessed at least once for approximately 86% of the sampled peritoneal patients. This compared to 85%, 85%, 85%, 81% and 75% during the previous five years. It must be noted that this finding did not demonstrate that adequacy was achieved in 86% of peritoneal patients, only that some measurement was taken to quantify the dose delivered. The findings were 68% of CAPD patients had a mean Kt/V of ≥ 2.0 and 70% of cycler patients with a daytime dwell had a mean weekly Kt/V of 2.1 while 61% of cycler patients without a daytime dwell had a mean weekly Kt/V of 2.2

Percent Of Adult Peritoneal Dialysis Patients Who Had Treatment Adequacy Measured, US, 1995-2002



The DOQI guidelines for PD adequacy include:

Kt/V urea ≥2.0; creatinine clearance ≥ 60L/week/1.73m² for CAPD patients

Kt/V urea ≥2.1; creatinine clearance ≥ 63L/week/1.73m² for CCPD with day dwell patients

Kt/V urea ≥2.2; creatinine clearance ≥ 66L/week/1.73m² for CCPD patients

Based on the DOQI guidelines, 68% of CAPD and 70% of CCPD patients had mean adequacy values that met the guidelines. This is an improvement from the previous year when 60% of CCPD patients met the goal. (Network-specific peritoneal adequacy data are not available.)

National 2002 CPM results of PD Adequacy

		Percent of CAPD patients	Percent of CCPD patients
		achieving Kt/V of 2.0	achieving Kt/V of 2.1
200	)2	68%	70%
200	)1	68%	62%
200	00	65%	60%
199	99	56%	52%

The Center for Clinical Measurement and Improvement within the Health Standards and Quality Bureau of CMS has not announced federal minimum standards for peritoneal dialysis performance. In anemia management, 36%of the sampled peritoneal patients had mean hemoglobin values of ≥11gm/dL in the 2002 study period. Twenty-nine percent did not have mean serum albumin levels of even 3.5 gm/dL using the bromcresol green method or 3.2 gm/dL using the bromcresol purple method. Finally, 81% of the sampled patients did not have mean serum albumin measurements of at least 4.0 gm/dL (BCG) or 3.7 (BCP). Although these percentages are low, they represent an improvement from the previous years.

All pediatric patients < 18 years identified as receiving in-center hemodialysis on December 31, 2001 were included in this project. The total number of included pediatric patients was 668. There were 24 pediatric patients from network 3 included in the data collection. The findings for the entire sample were 87% of patients had a mean delivered calculated, single session  $Kt/V \ge 1.2$ . In anemia management, 62% of patients had a mean hemoglobin of  $\ge 11$  gm/dL. A disturbing finding was only 26% of patients had an arteriovenous fistula. Nutritionally speaking, the pediatric patients had a mean serum albumin  $\ge 4.0/3.7$  gm/dL (BCG/BCP).

## Summary of how the Clinical Performance Measures Project affected the ESRD population

Network 3 met its responsibility to participate in this federal project. Eighty-five percent of the submitted hemodialysis forms and seventy-nine% of the peritoneal forms met project criteria and could be used for the analysis.

Participation in the federal Clinical Performance Measures Project and receipt of national and regional data profiles enabled the network's dialysis providers to compare their intermediate outcomes to those of their nephrology colleagues across the country. Published results prompted questions of why an individual facility's results might be lower than those of other regions of the country. Providers benchmarked their own facility-specific results to larger populations in other areas and strove to improve. It has been encouraging to have network 3 results improve each year and are consistent with the national average in dialysis adequacy. Data points served as triggers to improve and, by doing so, achieved CMS's purpose.

## Hemodialysis Adequacy Quality Improvement Project

In 2000, CMS directed all networks to create a quality improvement project focusing on adequacy of hemodialysis. The federal government accepted as a benchmark at least 80% of the hemodialysis population should have a URR of 65% or Kt/V of 1.2. According to the data from the Clinical Performance Measures, more than 80% of the hemodialysis population in network 3 had URR values > 65%.

The Medical Review Board and the Board of Trustees acknowledged that significant improvement had been achieved but that further improvement could be attained by again looking at the very beginning of the process, which is the hemodialysis prescription.

TARC had historical experience to believe this was an acceptable project. During the prescription project conducted in 1992, prescription and adequacy data were extracted from patients' medical records and it was learned that patients who were underdialyzed frequently had an inadequate prescription.

In 1999, a further test of the prior finding was conducted. A facility was asked to explain why the patients in their facility had URRs <65%; the response received was that the patients who had low URRs were also noncompliant with their treatment/ hemodialysis prescription. TARC reviewed data on all patients in

that facility that had URRs < 65%. None of the patients had varied from the prescribed treatment. Most of the patients had a prescription that could not achieve a Kt/V of 1.2.

The project idea document was developed and submitted to CMS officials for approval in 2000. After approval of the completed narrative plan was received the activity was initiated in 2001.

The goal of the Hemodialysis Prescription Adequacy Quality Improvement Project was to increase the number and percentage of patients who receive adequate dialysis, defined as a URR of 65% or Kt/V of 1.2. The immediate objectives were to increase the number and percentage of hemodialysis patients who:

- 1. receive doses of hemodialysis treatments of at least URR of 65% or Kt/V of 1.2; and
- 2. have prescriptions for doses of hemodialysis of at least a Kt/V of 1.3.

The project initially included 80 New Jersey facilities. The facilities had to have an ambulatory hemodialysis caseload of at least 20 patients to be included. Ultimately, 75 facilities participated in the project.

Facilities attended a project orientation session in September 2001. Data was collected for specified time periods. All participating facilities provided baseline data for the month of August. Some facilities also provided data for the month of November. Due to technical difficulties, the second data collection period was not completed until early 2002. The last data collection included data for the month of June 2002.

The project focused on one possible root cause of low delivered dose of hemodialysis, which is the prescription. Facilities were asked to provide identification information, the prescription data and adequacy-related data for all of their adult (at least 18 years old) in-center hemodialysis patients that dialyzed three times per week. Patients receiving hemodialysis using tandem or sequential dialyzers were excluded. Peritoneal dialysis patients receiving temporary back-up hemodialysis and transient patients were excluded.

The data were entered into a secure website. Once the prescription data was entered, the program calculated the prescribed Kt/V and the time needed to achieve a Kt/V of 1.3 based on the clearance of the dialyzer, the weight of the patient, and other factors. The expected outcome data was immediately available to facilities once the data was entered.

Facilities sent in electronic format pre and post-treatment blood urea nitrogen (BUN) values. Actual URRs were calculated and displayed on the viewer's computer screen. The viewer could then see for each patient: name, prescribed Kt/V, time needed to achieve Kt/V, current prescription time and current actual URR.

In addition to the content of the project, this activity was innovative in using current technology: a website with instant feedback for some components. However, there were technical difficulties that impacted the timeline of the project.

The project initially included 5,919 patients in 80 facilities in New Jersey. Five facilities withdrew from the project. Of those 75 facilities, 23 were identified as intervention facilities and 22 were identified as control facilities. It was expected that there would be a decrease in patients during the data collection time periods and that did occur. Improvement occurred in both groups.

The main outcome indicator was to improve the percentage of patients who had an adequate delivered dose of dialysis as measured by urea reduction ratio (URR) of 65% or more. Baseline data indicated that 85.7% of the intervention group and 86.7% of the control group met this indicator. The first process indicator was to have an increase in the percentage of patients that had an adequate prescription for hemodialysis, which would achieve a Kt/V of 1.2. Both groups improved but the control group improved

more than the intervention group. The intervention group initially had 43.5% of the patients with a written prescription that would achieve a Kt/V of 1.2 while the control group had 46.6% meeting the indicator. At remeasurement, the intervention group had 49.1% and the control group had 52.8% meeting the indicator. It is quite noteworthy that in 2002, only half of the patients had adequate prescriptions written. The final process indicator looked at those patients that were underdialyzed and their prescription. There was significant change in this indicator. Initially, 23.1% of patients project-wide had an adequate prescription despite the fact that they had inadequate delivered dose of dialysis. At remeasurement, 47.5% of patients had an adequate prescription despite that the inadequate delivered dose of dialysis.

## Assessment and Reduction of Catheters in Hemodialysis Quality Improvement Project.

In 2001, CMS directed all networks to conduct a quality improvement project on vascular access for hemodialysis. Each network selected a topic from the following 3 topic choice: stenosis monitoring, increase use of arteriovenous fistulae or catheter reduction: TARC selected the 3<sup>rd</sup> option.

The project idea and narrative plan were developed as a group effort with other networks that selected the topic, medical review board members and CMS representatives.

The goal of the project was to lower the number of patients with catheters in place for more than 90 days. Specifically, the expectations were:

- 1. All facilities will have a written process called a vascular access plan by which vascular accesses are assessed and documented and catheters are identified for further intervention.
- 2. Each patient will have a documented vascular access plan

Based on data from the Hemodialysis Improvement Project, facilities that had the highest percentage of catheters in the 3<sup>rd</sup> quarter of 2001 were selected to participate. A total of 26 facilities were selected: 20 facilities in New Jersey and 6 facilities in Puerto Rico.

A data collection tool was developed which included facility-based questions and patient-related questions. The facility-based questions asked if the facility had a written vascular access plan, if all patients had a vascular access plan, and other clinically relevant items. The patient-related items were to be completed only for patients with catheters and included the patient's name, if the catheter was in place for >90 days, why the catheter was in place as well as process items. Additional materials for facility use during the project included an algorithm, root-cause analysis tool, tracking tool and a tool kit with resource material for facility staff.

Meetings were held in May in New Jersey and Puerto Rico. Dr. Jeffrey Kaufman presented information on techniques, finances, and other topics related to vascular access. The project and requirements was described to participants.

All facilities in the network completed data collection tools for December 2001 as the baseline measurement and December 2002 as the remeasurement. The 26 selected facilities completed data collection tools at 2 other intervals. The data collection tool asked if the facility had a written vascular access program, an identified vascular access coordinator, assessment practices, and plans. The tool also asked for the list of patients with catheters, the duration of the catheter, why the catheter was in place and what was the status of surgeon referral.

The data was completed for the first three stat submissions by the end of the year. The final data collection period of December 31, 2002 was due in January of 200s. The analysis and report will be ready in 2003.

# PARTICIPATION IN THE CENTERS FOR DISEASE CONTROL NATIONAL SURVEILLANCE OF DIALYSIS-ASSOCIATED DISEASES, 2002, SURVEY ("CDC Survey")

### Vascular Access Types

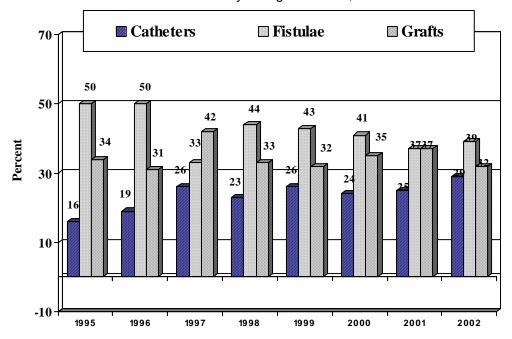
A well-functioning vascular access is required to achieve an adequate dose of hemodialysis. The National Surveillance of Dialysis-Associated Diseases 2002 survey, developed by the CDC, included vascular access questions. (This survey is usually referred to as the CDC survey.) The survey asked facilities to list the number of patients in their facility during the week of December 2 through December 7, 2001 who had an arteriovenous graft (AVG), arteriovenous fistula (AVF), cuffed catheter, non-cuffed catheter and port access device.

In 2002, 34% of Network 3 patients had an arteriovenous fistula. DOQI evidence-based guideline 3A lists the selection of permanent vascular access and order of preference for placement. In the guideline, the fistula is considered the preferred choice for permanent vascular access. The percent of patients in New Jersey with fistulas increased in the last three years from 27% in 1999 to 29% in 2000 to 30% in 2001 to 34% in 2002, which illustrates a slow increase in use. The prevalence of fistulas in Puerto Rico and the US Virgin Islands was on the decline for 3 years but that trend may have reversed. In 1996, 50% of the patients in the US Virgin Islands and Puerto Rico had fistulae, by 2000 the percentage decreased to 40%, in 2001, the percentage of patients with AVFs was 37%. In 2002, the facilities in the islands reported on the CDC survey that 39% of patients were being dialyzed via fistulae.

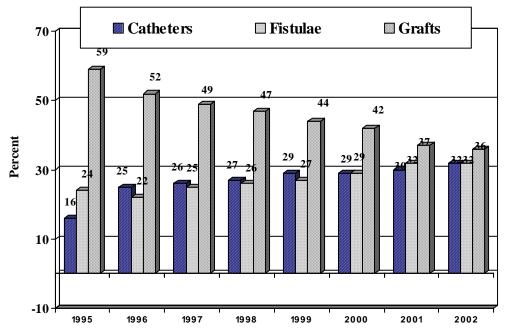
The percent of patients in New Jersey with arteriovenous grafts has been decreasing since 1995. In 2002 network 3 facilities reported that 35% of patients received hemodialysis via an arteriovenous graft. In 1995 New Jersey facilities reported 59% of patients had grafts, the percentage was reduced to 42% in 2000, and 38% in 2001. However, facilities reported that 29% of hemodialysis patients had catheters in 1999 and 2000 and increased to 31% in 2001. The percentage of patients in NJ dialyzing via catheter during the specified week in December 2002 was 34%. Three facilities reported having a total of 4 patients with port devices in NJ. This is a decrease from 2001 when there were 12 port devices in use.

The percent of patients in Puerto Rico/US Virgin Islands who received hemodialysis via a catheter varies slightly from 26% in 1999 to 24% in 2000, 25% in 2001 and 29% in 2002. The percentage of patients dialyzing via an AVG was 32%. One facility reported 1 patient with a port device.

Percent of Various Types of Vascular Access Used in New Jersey during December, 1995-2002



Percent of Various Types of Vascular Access
Used in Puerto Rico & US Virgin Islands during December, 1995-2002



Use of V	Use of Various Accesses During December, 1995-2002						
	New Jersey	_		Puerto Rico	Puerto Rico & USVI		
	Catheters	AVF	AVG	Catheters	AVF	AVG	
1995	16%	24%	59%	16%	50%	34%	
1996	25%	22%	52%	19%	50%	31%	
1997	26%	25%	49%	26%	33%	42%	
1998	27%	26%	47%	23%	44%	33%	
1999	29%	27%	44%	26%	43%	32%	
2000	29%	29%	42%	24%	41%	35%	
2001	31%	30%	38%	25%	37%	37%	
2002	32%%	32%	36%	29%	39%	32%	

According to the reported data on the CDC survey, there were 3,585 patients in network 3 who were dialyzing via a catheter (including port devices) during the identified week of data collection. In previous years, the CDC survey asked additional follow-up questions including why catheters were being used. That component was eliminated from the survey.

## Dialyzer Reprocessing

Of the 129 facilities that completed the CDC survey, 69 facilities (53%) (44 in New Jersey and 25 in Puerto Rico), reported that dialyzers were reprocessed for some or all patients. The 2 facilities in the US Virgin Islands reported that they did not reprocess dialyzers. These characteristics are significantly different from the previous year when 68% of facilities reported reusing dialyzers.

The disinfecting methods/agents that were reported were as follows:

Methods/Agents	Number (%) of Facilities
Peracetic acid	43 (62%)
Formalin	23 (33%)
Glutaraldehyde	2 ( 3%)
Heat	1 ( 2%)

## Preventive Measures and Issues: Hepatitis

Of the 129 reporting facilities, 113 facilities (87.5%) reported testing patients for Hepatitis C antibodies. Of those facilities that tested for Hepatitis C antibodies, 975 patients were reported having antibodies to Hepatitis C. Of these patients, 53 patients converted from Hepatitis C antibody negative to antibody positive in 2002. The conversion rate more than doubled as 22 patients were reported as converting to Hepatitis C antibody in 2002.

Ninety-eight per cent of facilities tested patients for the presence of Hepatitis B surface antibodies. Within the facilities that tested, 116 patients were reported as having Hepatitis B surface antigens and 10 patients converted to Hepatitis B antigen positive in 2002. For the first time in years, there was a decrease in the number of patients that were offered the vaccine. Less than half of the patients (47%) ever received all 3 doses of the vaccine.

Year	New	Puerto	US Virgin	Total
	Jersey	Rico	Islands	
1995	1,087	673	0	1,760
1996	1,097	841	0	1,938
1997	2,332	1,003	0	3,335
1998	2,821	1,136	30	3,987
1999	3,079	1,181	29	4,289
2000	3,610	1,364	18	4,983
2001	4,380	1,458	14	5,852
2002	4,091	1,333	0	5,424

Ninety-eight percent of facilities reported that they routinely test seronegative patients for Hepatitis B surface antigen. Most facilities (72%) perform testing annually for those patients who are Hepatitis B surface antibody positive. Other facilities test monthly, every 2 months, every 3-6 months and every 7-12 months.

In 2002, the number of patients that were reported as Hepatitis B surface antigen positive was low. An unexplained variation in the number of patients that converted from Hepatitis surface antigen negative to positive was reported over the year

Year	New Jersey	Puerto Rico/USVI	Total
1995	29	2	31
1996	106	4	110
1997	12	11	23
1998	6	5	11
1999	21	0	21
2000	4	1	5
2001	10	1	11
2002	8	2	10

The number of dialysis staff in the network who had direct contact with patients or equipment during the week surveyed was reported to be 2,655. Almost 85% of the staff had received at least 3 doses of the Hepatitis B vaccine.

New area of preventative processes and practices were explored this year on the survey. There was an interest in where medications from multidose vials were drawn into syringes. Half (50%) of the facilities prepared the medications in a separate medication area. The second most common practice was to prepare the medications on a medication cart in the treatment area. Of interest was a number of units indicated that the facility receives prefilled syringes for some medications (e.g., erythropoetin) and fill the heparin syringes in the unit.

The survey asked where clean supplies were kept and what was done with unused supplies. Slightly more than half (53%) of facilities kept the clean supplies on a common cart within the treatment area. About a third (36%) of facilities utilized an area separate from the treatment area. The majority (77%) of facilities discarded unused supplies. The supplies in question were adhesive tape, unopened needles, syringes, alcohol wipes, etc.

An interesting question asked if external transducer protectors were used during hemodialysis. This question reflects the hemodialysis system in use as well as practices. Approximately 76% of facilities use systems with external transducer protectors. All but 1 facility stated that the filters are changed between each patient treatment.

The survey contained a general question, which asked if the facilities were aware of the Recommendations for Preventing Transmission of Infections Among Chronic Hemodialysis Patients published by the CDC in 2001. Most facilities (95%) were familiar with the recommendations publication and had a copy in the facility. Of those that did have a copy, 6&% made some type of change to the infection control practices as a result of these recommendations. TARC distributed a copy of these recommendations to every facility in the network in the fall of 2002.

Human Immunosuppressive Virus and Acquired Immune Deficiency Syndrome

For the last few years, the CDC asked only 2 questions about HIV. CDC asked how many patients who were dialyzed during the specified week were known positive for HIV and of those patients, how many were known to have AIDS? A total of 312 patients were listed as HIV positive. The number of patients reported as having AIDS was 99. These numbers should be kept in perspective of the facilities' reporting and confidentially practices.

Number of HIV Positive and AIDS Positive Hemodialysis Patients

Year	New Jersey		Puerto Rico/USVI	
	HIV +	AIDS +	HIV +	AIDS +
1995	269	138	42	23
1996	245	134	35	19
1997	269	134	36	25
1998	284	117	42	26
1999	261	93	25	15
2000	227	55	26	11
2001	291	77	35	11
2002	280	90	32	9

## **Infections**

Vancomycin-resistant enterococcus (VRE) is a concern for dialysis patients. Last year, 29% of the facilities reported at least one case of VRE in their facilities and in the prior year, 37% of facilities reported at least one case of VRE in their facilities. In the latest survey, 31 facilities reported at least 1 patient with VRE and 6 facilities reported 5 to 9 cases of VRE. No facility reported greater than 10 cases. This seems to indicate a decrease in the number of patients with VRE and the number of facilities with VRE cases. New Jersey facilities reported a total of 57 VRE cases and the islands reported 4 cases.

For those facilities that did dialyze patients who were identified as having VRE, 10 facilities *always* treated these patients in separate rooms and 9 treated VRE patients in separate rooms *sometimes*. Most facilities stated they never treated VRE patients in a separate room.

Patients with Methicillin-Resistant Staphylococcus Aureus (MRSA) were reported in 81 facilities, networkwide. The number of patients with MRSA increased each year that it has been surveyed.

Year	New Jersey	Puerto Rico/USVI	Total
1995	31	3	34
1996	42	4	46
1997	45	4	49
1998	50	10	60
1999	61	7	68
2000	67	8	75
2001	71	6	77
2002	74	7	81

## How participation in the CDC Survey affected the ESRD population

Participation in the CDC survey ultimately provides a service to hemodialysis providers and consumers. Responding to questions on the survey prompts those participating in internal quality improvement programs to be alert to the need to track certain infections and conditions in their facility. Questions are added, deleted or modified to keep current with issues. By improving local monitoring, better data will be available to share with the CDC and renal community at large.

Gathering data at a facility level encourages self-analysis in instances when a provider did not track an issue on its own during the year. After data are summarized and analyzed by the network, facilities may compare their experience and benchmark. For example, the facilities that reported high numbers of noncuffed catheters may question why their facility is still using cuffed catheters when clearly, the majority of facilities are using the recommended cuffed catheters.

As the Centers for Disease Control and Prevention distributes its summary report, local renal communities will be encouraged to further address disease prevention. Medical review boards and individual facilities will be able to profile and compare local results with national trends and identify opportunities for positive change.

# PROVISION OF TECHNICAL ASSISTANCE, EDUCATIONAL MATERIAL AND PROBLEM RESOLUTION

## Summary of educational and other materials provided to facilities and/or consumers

Whenever possible, TARC provided informational material, technical assistance and guidance or made referrals to appropriate resources to assist facilities and consumers improve the quality of care and life for consumers. The network strives to be sensitive to local renal community needs and familiarizes others with its role in the CMS contract. This includes coordinating activities and participating with the larger renal community. These requests are received by letters, faxes, phone calls, the Website, and emails. Below are some examples of how TARC assisted to assure that ESRD consumers received the care they needed and providers had necessary information:

- TARC staff received numerous telephone calls from both ESRD and non-ESRD consumers with questions about Medicare coverage rules. Some information was provided directly, other consumers were referred to their nephrology social workers, and still others were referred to the ESRD Medicare coordinator.
- February 20, 2002, a mailing was sent to all dialysis and transplant administrators regarding adult immunizations. The mailing was sent to encourage these facilities to participate in the immunization process for their patients and their staff.
- Medical review board physicians responded to clinical questions posted on the web site and by email. Questions were about such topics as: results of kidney transplants, nutrition, allergic reactions to dialyzers, polycystic kidney disease, possibilities of success for renal transplants.
- March 14, 2002, TARC sent an action memorandum to all New Jersey facilities about the
  coordination of water supply companies some future elements of concern. However, in order to
  do this, TARC requested that each facility forward to TARC the name of the facility's current
  water supply company, their address, telephone number, email and contact person.

- Information regarding transplant centers in New Jersey and websites with renal information was given to an individual whose son's renal function was decreasing. Time was spent discussing transplant lists, UNOS, and transplant centers in New Jersey.
- Copies of the 2002 Kidney Camp directory which was prepared by the National Kidney Foundation's Patient and Family Council were sent to New Jersey pediatric dialysis and transplant units.
- April 4, 2002, facility mailing lists were sent to the American Kidney Fund in order to coordinate conferences and to update their mailing list.
- TARC provided information on preemptive transplantation to an individual in the US Virgin Islands. In addition, information was given on the dialysis center located on St. Thomas in the event that the individual required dialysis prior to the scheduled transplant.
- April 19, 2002, TARC sent a memorandum to all Renal Administrators and Federal Forms
  Preparers informing them that the data system currently used by CMS would be replaced by
  SIMS in July 2002. All forms must include the proper name and numbers the same as stated on
  the social security card (HIC and social security).
- Facility-specific charts of network goal performance were distributed to chief executive officers at all Medicare ESRD facilities.
- May 1st, 2002, in response to the FDA notice, TARC faxed a notice regarding a volunteer recall from Wyeth Pharmaceuticals and ESI Lederle of ALL lots of heparin sodium injectables to all of its dialysis providers.
- Information regarding transplant facilities was sent to a physician in Puerto Rico.
- May 21, 2002, a listing of dialysis facilities in Monmouth County was sent to the Monmouth County Correctional Facility to assist in scheduling dialysis services for inmates.
- TARC performed three quality audits during their visit to Puerto Rico. Anemia management was an area of concern. Tools for remediation were shared with staff and leadership. Reviews of each audit were given to the medical directors and management of each facility.
- June 12, 2002, the network distributed the 2002 Unit Specific Reports, Facility Data Reports, and the Dialysis Facility Compare Reports from CMS to the facilities.
- TARC received many phone calls seeking advise about abusive and disruptive patients. Each facility was given individual attention and suggested to reference their facilities policy and procedures in relation to each specific incidence. Additional information sent upon request. When deemed appropriate a facility was referred to their legal department. All facilities were instructed to thoroughly document all incidents.
- A copies of the most recent chronic dialysis patient origin report by zip code and age group summary were sent to suppliers upon request (twelve for 2002).
- July 10, 2002, as requested, a copy of the annual report was sent to the Latin American Registry
  of Dialysis and Renal Transplantation in addition to information about content and accessing the
  TARC website. Information on immunizations was sent to the director of a local transplant center.
- TARC responded to many data requests from vendors of dialysis supplies/equipment.

- July 19, 2002, the Unit Self Assessment Manual (USAT) developed by the Life Options Rehabilitation Council (LORAC) was sent to all facilities in Network 3.
- TARC sent the CDC memo regarding the "Revised Recommendations for Single-Use Intravenous Medication Vials in End-Stage Renal Disease(ESRD) to all facilities.
- September 13, 2002, the annual Goal Mailing was sent to the C.E.O., medical director, administrator and facility quality improvement contact person of all Medicare-Certified ESRD Facilities. in New Jersey, Puerto Rico and Virgin Islands.
- The network dialysis facilities were provided with historical data specific to each facility's anemia management and adequacy of dialysis outcomes. Based on historical performance, and upon the recommendation of the boards, the facilities not meeting TARC goals were asked to submit an improvement plan for these two areas of care. Network staff provided the facilities with the tools to assist in the development of the improvement plan.
- September 19, 24, & October 3, 2002, TARC held Patient Safety Meetings in northern, central and southern New Jersey. The purpose of these meetings was to convey the need to increase the awareness for and the promotion of patient safety. TARC plans to replicate these meetings in Puerto Rico during their visit in 2003.
- September 25, 2002, the Executive Director spoke at the meeting of Council of Renal Social Workers.
- TARC in response to a facility's questions about the SMR component of their unit specific report (USRs) interacted with the University of Michigan. TARC and the contact at the University of Michigan agreed to disagree on the logic if not the statistical soundness. The data in question would be suppressed from the SSA material and DFC. CMS announced at the VISION training meeting in September that Dr. Paul Eggers and the University of Michigan will be reviewing the methodology used for SMR calculation.
- September 26, 2002, a copy of the monthly caseload form was sent to the USRDS Special Studies Centers for QOL/Rehabilitation, Nutrition, and Economics. The USRDS is designing a research study that will be implemented through the Networks.
- October 15, 2002, administrators of all dialysis and transplant facilities were sent the annual distribution of educational material and Federal forms.
- TARC assisted a mother with two children on dialysis by providing information on additional available resources:: state and federal programs, county health special children's programs, catastrophic children's fund, and county transportation for a child returning to school.
- October 22, 2002, the 2001 Annual Report for network three was posted on the website.
- November 6, 2002, TARC held their annual council meeting and educational program at the Sheraton Woodbridge Place Hotel, Iselin, New Jersey. Home dialysis was the main theme focusing on all aspects of home treatment, i.e., home hemodialysis, peritoneal dialysis, reimbursement. The program also contained a segment addressing "Patients Who Try Our Patience".

- November 7, 2002, the 2002 VHA dialysis facility-specific clinical performance measures report
  was sent to the medical director and the director of nursing for the New Jersey and Puerto Rico
  VA facilities.
- TARC answered several calls from social workers with questions regarding transportation while a
  patient was in rehabilitation.
- November 18, 2002, the 2001 Annual Report was sent to all dialysis and transplant facility administrators.
- TARC provided information to a transplant patient regarding prescription drug plans.
- November 18, 2002, the social workers in network three's dialysis facilities were sent the booklet "Effective Strategies for Improving Employment Outcomes for People with Chronic Kidney Disease", produced by the University of Arkansas Region VI Rehabilitation Continuing Education Program. The booklet will be a useful resource for both newly diagnosed patients and new dialysis social workers.
- Information was provided to the spouse of patient regarding home hemodialysis training programs and facilities that offered a 4th shift in their geographic area.
- November 20, 2002, a Vision software training session and WebEx voice/computer session for non corporate providers was held in Holy Name Hospital, Teaneck, New Jersey.
- TARC staff answered a call from the spouse of a dialysis patient who will go to a rehab facility upon discharge. The spouse had questions as to whether or not Medicare would cover transportation costs between the rehabilitation facility and the dialysis facility.
- November 25, 2002, TARC shared their network specific rehabilitation efforts information with the Life Options Rehabilitation Council.
- TARC provided a facility administrator with a copy of the TARC medical review board's recommendation for physician documentation in dialysis unit charts.
- December 3, 2002, the CMS publications, Control Your Diabetes for Life, and Medicare and You 2003, in both English and Spanish and an article providing an overview of hepatitis C (used for staff education) were sent to the administrators of dialysis and transplant facilities.
- Copies of Patients Rights and Responsibilities, and Consumer Grievance Procedure, in both English and Spanish were sent to each new network facility for distribution to all in-center and home patients.
- TARC provided information with a general history of the ESRD networks and network three, per the request of .an individual working for a healthcare consulting firm that tracks national trends in healthcare.
- TARC responded to a phone call from an individual requesting the names of New Jersey long term care facilities offering hemodialysis services. The name and phone number of the one known facility in New Jersey was given to the individual as well as the phone number for the New Jersey State Department of Health and Senior Services.
- TARC sent a case manager in a non-ESRD hospital a list of dialysis facilities in New Jersey to aid in a patient's discharge planning.

- TARC responded to a call from an insurance company representative who had questions about reimbursement for transportation to dialysis.
- A recently retired dialysis patient called TARC with questions regarding a pending change in their insurance coverage. The different options were discussed and additional information was given about a local program known to assist senior citizens. The patient was advised to contact the social worker at their dialysis facility as well as their employer.
- TARC sent copies of the 2003 "Medicare and You" to all dialysis and transplant facility administrators.
- December 18, 2002, the involuntary discharged patient survey was sent to all of the hemodialysis units social workers in network three.
- Network staff presented an overview of the function and purpose of the ESRD networks at a meeting of a local chapter of the AAKP.
- TARC assisted a working patient in obtaining a dialysis schedule that would allow the patient to continue working full time.
- New facility binders with network information, data requirements and resource material were sent
  to ten new Medicare program facilities. (Material for new facilities included the anemia guide,
  regulatory requirements, quality of care improvement material, current CMS studies and network
  projects, data reporting requirements, and clinical resource articles.)

TARC annually distributes the following information to each facility In an effort to apprise the renal community of activities within the network area.

- ESRD program goals and the network activities to achieve the goals;
- Regional patterns or profiles of care as provided in the Clinical Performance Measures Annual Report;
- The network's annual report;
- Results of quality improvement projects:
- Other materials such as journal articles and pertinent research information that renal providers may use in their quality improvement programs;
- Treatment options and new ESRD technologies available for consumers; and,
- State and regional vocational rehabilitation programs available in the network area.

During 2002, these materials were distributed by mailings to facility medical directors, head nurses, administrators, quality improvement coordinators, and several were also given as handouts at network-sponsored meetings such as the annual Council meeting. In addition to mailings, the network staff responded to individual requests for data and information throughout the year. A sample list of materials distributed follows:

- Network 3 Goals 2000 2003;
- Medicare and You 2003 (Spanish and English)
- Your Medicare Rights and Protections(English)
- Your Medicare Benefits(Spanish)
- Medicare Coverage of Dialysis and Kidney Transplant Services(Spanish)
- Choosing a Medigap Policy
- o Preparing for Emergencies

- o Dialysis Facility Compare: Guide to Medicare Certified Dialysis Facilities
- Understanding Your Access Options, AAKP
- CMS 2746 forms(death notices)
- Patient Grievance Procedures(English and Spanish)
- Patients Right and Responsibilities(English and Spanish)
- o General Principles of Infection Control: Up to Date
- Staphylococcus Aureus Resistance to Vancomycin US 2002, MMWR
- o CDC Recommendations for Single Use Intravenous Medication Vials in ESRD, Facilities Memo
- Guidelines for the Prevention of Intravascular Catheter-Related Infections, MMWR
- o Where Are All the Fistulas?, Jeffrey Sans and Mike Perry
- o Improving the Quality of Hemodialysis Treatment, Sehgal, et al., JAMA
- Serum Albumin Measurement in Dialysis Patients: Should it be a measurement of clinical performance?, Alan S. Kliger, Journal of Renal Nutrition
- o The behavior contract as a POSITIVE patient experience, Ramiro Valdez, Phd
- The Importance of Effective Communication in the Dialysis Facility Setting, Arlene Sukolsky, CD
   N
- Who will you call when disaster strikes in the dialysis facility, Matthew Arduino, NN&I
- Dialysis Access Failure: An Indication for Immediate Kidney Transplantation, David Laskow and Nasimul Ahsan, Seminars in Dialysis
- o Keys to a Long Life, LORAC
- Nocturnal Home Hemodialysis
- o A Multidisciplinary Approach to Meeting Growth & Development of the Pediatric Patient

## How provision of educational materials affected the ESRD population

Patients who participate in their health care decisions have many positive benefits. TARC feels an ESRD consumer should be afforded the opportunity to become educated in their disease and treatment options so they may become participatory in their health care decision processes. A sense of control and empowerment results in a greater sense of well being and positive outcomes. A consumer educated in their rights and responsibilities takes greater ownership in their role. A consumer educated in the grievance procedure knows they are not helpless when their care poses a troublesome situation. A consumer educated in quality indicators is able to track their treatments and know why certain modalities are preformed. All of these facets help to make a patient feel they are truly part of a health care team striving to achieve the optimum level of health for that patient. The continuum of care for the ESRD consumers spans a broad spectrum of providers. TARC, through the provision of educational materials, hopes to clarify some of the confusing elements and simplify the road of renal replacement therapy.

ESRD consumers indirectly benefited from their providers becoming informed about and responding to both the CMS and the network-specific goals which strive for quality renal replacement services. Existing or hopeful providers used network data to plan expansion programs and/or new facilities, assisted consumers by making treatment available in more locations or on additional shifts. Overall, since the ultimate purpose of both the network and the Medicare-certified ESRD facilities operating within the network area, is to serve renal consumers, all renal-related educational materials eventually enhance patient care delivery.

## Summary of technical assistance provided to facilities and consumers

TARC provided technical assistance, guidance, and appropriate referrals for facilities and consumers. The network office identified available providers for consumers seeking ESRD services whether they need a full-time or transient treatment facility. Additional aspects of technical assistance include the

network's role in investigating and resolving patient issues and concerns before they became complaints or grievances.

The network assisted newly-approved Medicare ESRD facilities in the development of disaster plans. The plans included provisions for weather-related or other emergencies that would affect the unit's ability to provide renal replacement therapy.

Bulletins and updated medical material for professional staff from the Centers for Disease Control and Prevention were faxed and e-mailed to all New Jersey facilities in addition to web sites with current medical information on anthrax.

## How educational and technical assistance affected the ESRD population

TARC assisted the consumers in the facilitation of travel arrangements by providing the names, addresses, telephone numbers and names of key dialysis unit personnel in dialysis units for transient treatments.

TARC provided the facilities with information, i.e., emergency manuals, web resource lists, to enable them to prepare for weather-related or other emergencies. Using these tools, each facility can develop a unit specific plan to provide care with the least amount of disruption for its consumers.

TARC, through its quality audits, provides assistance to facility managers and medical directors in the recognition of unsafe practices, i.e., water treatment, bicarbonate preparation, machine disinfection. TARC also provides mandatory safety programs for their facilities to identify areas of increased risk for medical errors. All of these efforts are directed toward the ultimate goal of providing an environment of care that is not only safe but will produce optimum outcomes for all ESRD beneficiaries.

## Improving data reporting, reliability and validity among ESRD facilities, ESRD Networks, and CMS (or other appropriate agency).

#### Medical Information System Goal

Enable an efficient patient-specific database with quality improvement modules that is consistent with CMS's electronic transmission initiatives.

Activity: Each newly approved and existing facility will assure a system is established/maintained that assures knowledgeable facility data reporting personnel.

Activity: Ensure timely and accurate submission of 90% of forms generated.

Activity: Each facility will enable internal data processing systems that will support CQI activities, efficient electronic data transmission and the use by professional staff of internet resources.

Activity: TARC will provide periodic data processing instruction for facilities.

Each facility will track and report progress in various indicators via web site data entry.

The Chronic Renal Disease Medical Evidence Report form (CMS-2728) was the initial reporting form for all persons with end stage renal failure who began a regular course of dialysis or had a renal transplant as a first form of therapy. The form was completed and submitted to the TARC office by ESRD Medicarecertified facilities and Veterans Administration Medical Centers according to federal regulations. Submission is expected within forty-five days of the start of renal replacement therapy, whether or not the patient applied at that time for financial coverage under the federal Medicare program. The ESRD Death Notification form is due within thirty days of an ESRD patient's expiration.

TARC staff entered data from the CMS-2728 forms into computer software supported by the federal government. If data required on the form were missing or incompatible with software assumptions, the form was rejected by the software and returned to the facility for correction. There has been a steady improvement in reporting accuracy, network-wide.

Input forms employed to maintain the network patient-specific data system included:

- Monthly Caseload Changes/Census form;
- Chronic Renal Disease Medical Evidence Report (CMS-2728); and the
- ESRD Death Notification form (CMS-2746).

Forms used to check and reconcile data that were submitted as required, included:

- ESRD Facility Survey (CMS-2744);
- Accretions lists from CMS;
- Edit Reports from CMS; and
- Federal REBUS on-line system.

Network staff validated and monitored the accuracy and timeliness of facility data submissions from all dialysis and transplant programs in New Jersey, Puerto Rico, and the United States Virgin Islands. Staff used a computer-based facility timeline system designed for this purpose. During 2001, facility compliance was monitored for each of the federal MIS forms mentioned. Semiannually, the data file was run through customized programming. Two aspects of facility feedback were generated for each of the required forms:

- Compliance rate summary report; and
- Detail of each form submitted.

The compliance rate summary report presented calculations of the total number of forms transmitted, the number of forms submitted that were within the thirty or forty-five day goal, the number of forms with errors, and the percent compliance by each Medicare-certified dialysis facility. The detail report generated specified the patient-specific information on each form.

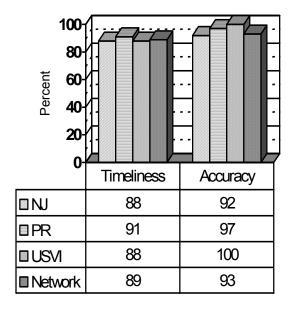
Data submission compliance reports were distributed to facility administrators with the expectation that they would positively recognize those employees who achieved the data reporting goal of submitting forms within thirty or forty-five days of events being reported. On the other hand, if the compliance reports reflected forms that were overdue and outstanding, administrators were expected to follow-up with their employees to correct factors contributing to data reporting non-compliance. Trend data that showed persistent non-compliance identified specific facilities that were asked to prepare formal improvement plans.

#### Chronic Renal Disease Medical Evidence Report (CMS-2728):

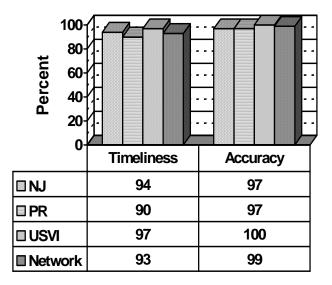
There were 3,273 CMS-2728 forms submitted from New Jersey dialysis programs. Of these, 3,042 (93%) were completed accurately; therefore, the accuracy requirement was met in the state for that federal form. Chronic Renal Disease Medical Evidence Report forms were to have been submitted to the network office within forty-five days of the initiation of a regular course of dialysis. Of the forms submitted, 2,948 (90%) met CMS's timeliness criterion.

Facilities in Puerto Rico submitted 1,224 forms of which 1,111 (91%) were on time and 1,139 (93%) were completed accurately. Thirty-nine Medical Evidence Report forms were received in the network office from the US Virgin Islands, 36 (92%) were on time and 34 (87%) were completed accurately. Improvement was noted in timeliness and accuracy of the forms submitted for New Jersey and Puerto Rico and the US Virgin Islands.

Percent of CMS-2728 Forms Received by Timeliness and Accuracy CMS's Goal: 90% Compliance.



Percent of CMS-2746 Forms Received by Timeliness and Accuracy CMS's Goal: 90% Compliance



## ESRD Death Notification form (CMS-2746):

New Jersey dialysis units sent 2,652 death notification forms during the year, of which 2,249 (85%) were on time and 2,634 (99%) were accurate. New Jersey fell short of the timeliness requirement and exceeded the accuracy requirement . Puerto Rico's dialysis programs submitted 985 death forms of which 851 (86%) were on time, and 981 forms (99%) were accurately completed. Puerto Rico exceeded the goal for accuracy and has significantly improved in the timeliness requirement. The two Virgin Island facilities sent 20 death forms; 19 (95%) were received on time and all 20 forms (100%) were accurately completed.

In 2002, the annual mailing included facility performance goal charts and the CMS requirements for ESRD forms compliance.

Reminders of what patients should be reported as "new" versus graft failures, transfers, and modality changes were included in the notice. The facilities were provided with the new change of name and address form that must be completed and sent with the monthly census report.

## Patient Tracking System Reporting Goal

In addition to receiving, processing, and transmitting data reported on the federal medical information system forms the network maintained a patient tracking system that followed end-stage renal disease consumers through changes in treatment modality and setting. Changes in provider were also tracked. These activities were necessary to support federal quality projects and special studies. Monitoring patient events was also necessary for the reconciliation of the federal ESRD Facility Survey, preparation of facility profiles for goal achievement for home dialysis use and referral, and local quality of care improvement efforts.

To accomplish patient tracking, all facilities notified TARC of all patient status changes on a monthly basis. Any change in the dialysis caseload was noted, including:

- Newly-diagnosed ESRD consumers who started a regular course of dialysis;
- Changes in modality during the month (e.g., Hemodialysis to CAPD);
- Changes in setting during the month (e.g., CAPD patient who went home);
- Transfers into or out of the facility during the month;
- Returns to dialysis after renal transplant grafts failed;
- Restarts to dialysis after temporarily regaining kidney function;
- Patient deaths:
- Discontinuance of dialysis treatment;
- Patients who became lost to follow-up; and
- Patients who regained native kidney function to the extent that dialysis was stopped.

## Computer Technology Goal

To facilitate ease of data development and tracking within dialysis programs, the network set a goal for 2000 that, if unavailable, facilities would investigate the use of computer technology for quality improvement activities.

During the year, network facilities reported various approaches to this goal. Some facilities purchased commercial quality monitoring systems and began to apply them to their internal quality activities. Other facilities had computer data profiling available centrally to support their improvement efforts. Physician medical directors of other facilities set up data tracking systems for use in monitoring changes over time.

In New Jersey 95 (100%) of the 95 facilities that completed the annual ESRD facility survey reported that they had the ability to utilize computer software programs for quality improvement activities in 2001. At the end of the year in the islands, of the 32 facilities that had ambulatory caseloads 32 (100%) reported computer capability for quality projects.

Ninety-three of New Jersey facilities (98%) reported that they had internet capability and e-mail available in the facility. In Puerto Rico and the US Virgin Islands, 24 facilities (75%) reported that they had internet and e-mail capabilities.

While there was a great deal of variability in computer capability among facilities in the network at the end of 2001, the goal to enable the utilization of computer technology for data processing, CQI activities, and access to the Internet has significantly improved. The expectation is that all facilities will be conducting data entry of federal forms as well as quality improvement data via computer.

There remain opportunities for continued improvement for using data and responding to analysis to enhance care to consumers. Another ongoing challenge is to provide guidance to new dialysis programs opening in the network area with no frame of reference for quality monitoring and improvement.

 Establishing and improving partnerships and cooperative activities among and between the ESRD Networks, QIO's, state survey agencies, and ESRD facilities/providers

CMS encourages the networks to establish and enhance partnerships with other health agencies and groups. During 2002, the network collaborated with the CMS regional offices (ROs), state survey agencies (SAs), other sections of government, quality improvement organizations (QIOs), vendors and interested agencies to improve the quality of care provided to consumers within network 3. These activities included sharing information to assist SAs and ROs in conducting their legislative responsibilities. Quality issues were referred as needed. Assistance was also given to other agencies in investigating the quality of renal replacement therapies.

Health and safety problems and complaints were referred to the appropriate state agency for investigation and resolution during 2002. When the state investigation was completed the findings were shared with the network. The network had telephone conversations about ongoing concerns with state agency personnel both in New Jersey and on the islands. TARC sent the state agencies copies of the network's annual report and pattern analysis reports. TARC staff attended the CMS sponsored state agency data meeting in Maryland which was attended by representatives from all of the state agencies.

Network 3 staff shared the TARC annual report with organ procurement agencies (OPOs) serving the various geographical sections of New Jersey, Puerto Rico and the US Virgin Islands. TARC staff corresponded with the OPOs to request data on organ recovery and transplantation activity in addition to information about kidney recipients, potential organ donors, actual organ donors and the donor consent rate.

Contacts between TARC and state agencies were made in reference to new facility approval and paperwork submission to the CMS regional offices. This was necessary since TARC could not maintain accuracy in the patient tracking system for CMS when non-ESRD providers were treating large numbers of consumers.

Members of the New Jersey state agency attended the annual meeting offered by TARC.

TARC representatives met with the New Jersey Renal Administrators Association. Network staff participated upon request at ancillary professional staff meetings as well as patient-sponsored meetings. TARC representatives also attended educational programs offered by facilities, professional organizations and corporate sponsors which facilitated interaction between network and unit staffs. TARC staff presented at the AAKP meeting in April.

More specific information concerning facility interaction is contained in a prior section titled, *Provision of Technical Assistance, Educational Material and Problem Resolution.* 

The network met its responsibility in 2002 to partner with other governmental agencies and contractors to enhance the safe and therapeutic delivery of dialysis and renal transplantation.

## Evaluating and resolving patient grievances

TARC may receive a written or oral complaint or grievance from an ESRD consumer, consumer representative, family member, friend, or others concerning either dialysis or transplant providers.

Referrals of ESRD consumer complaints or other concerns may be received from professional review organizations, state agencies, Medicare hotline numbers, and Medicare intermediaries. When an oral grievance is received, the person taking the complaint will usually be asked to document it in writing. During complaint investigations consumers may designate representatives to act on their behalf. Immediate investigation is started for a potentially life-threatening issue.

Consumers are encouraged to use facility internal processes prior to referring a grievance to the network. When a patient does not wish to use the facility process (it is not mandatory that consumers use the facility grievance process) they may contact the network for assistance.

The network's responsibility for complaints/grievances is to review issues raised and determine the required action, i.e., investigation or referral. The network role in resolving grievances varies depending on the situation. Attempts are made to resolve grievances by acting as an investigator, facilitator, referral agent or coordinator between a patient and the provider.

#### 2002 ESRD Patient Grievance

There were no formal grievances filed.

While there were no formal grievances filed during 2002, network staff addressed many concerns, issues, and complaints. A sample of interactions follows:

TARC assisted a dialysis facility in obtaining information to complete a CMS 2728 form. The facility had accepted a patient as a transient and later realized that the patient had transferred to the facility permanently. The patient had been discharged from a non-renal facility.

Staff received a call from an individual whose parent was receiving acute dialysis services. Staff gave the individual the names of dialysis facilities within a reasonable distance from where the parent lived.

TARC received a call from a patient's relative expressing concerns about the staffing in a dialysis facility in St. Croix. TARC contacted the facility and requested multiple data submissions to assess if the proper compliment of staff was caring for the patients. TARC found some questionable staffing ratios and contacted the proper governmental agencies to continue investigation.

TARC annually distributes copies of its network grievance procedure to all Medicare-certified facilities within New Jersey, Puerto Rico, and the US Virgin Islands. Facilities, in turn, make these available to their consumers via patient bulletin boards, handouts in dialysis waiting rooms and in orientation packets to all new consumers. During the year, as new facilities opened and became Medicare-certified, a supply of the network grievance procedure was sent with the orientation and resource notebooks.

During 2002, facilities in network 3 met their obligation for distributing the network grievance procedures and for handling and addressing issues of patient concern at the facility level.

## 4. SANCTION RECOMMENDATIONS

No facility sanction was recommended to the CMS in 2002.

## 5. RECOMMENDATIONS FOR ADDITIONAL FACILITIES

In all three geographic areas of Network 3, access to dialysis therapies is within reasonable travel distances from ESRD consumers' homes. At the end of 2002, no new dialysis facilities were recommended for New Jersey, Puerto Rico, or the US Virgin Islands.