There is not any present moment that is unconnected with some future one. The life of every man is a continued chain of incidents, each link of which hangs upon the former. The transition from cause to effect, from event to event, is often carried on by secret steps, which our foresight cannot divine, and our sagacity is unable to trace. Evil may at some future period bring forth good; and good may bring forth evil, both equally unexpected.

Joseph Addison, "Happiness Not Independent"
The ESRD program is typically characterized through growth in the absolute counts of new and existing patients over time. By normalizing these counts to rates, which take the overall U.S. population into account, and adjusting these rates for age, gender, and race, we can identify changes in the population which generates the ESRD incident at-risk population over time. To insure that each patient beginning ESRD treatment has a unique identification, the submission of a Medical Evidence form (2728) has been required for Medicare patients since 1978 and for all patients since 1995. For some patients, however, multiple forms are submitted. This can happen when patients change providers early in their treatment, or receive therapy for acute renal failure, discontinue dialysis, and restart therapy at a later time with a different provider. In addition, some patients—such as those covered by employer group health plans (EGHPs)—are not immediately eligible for Medicare, and may have one form completed at the start of therapy and another when eligibility begins. This issue of duplicate Medical Evidence forms creates a considerable problem in determining the true incident population count. This year, however, to more completely reconcile the patient records, and to address patient modality for non-Medicare and lost-to-followup patients, the USRDS—with help from CMS and the ESRD networks—has added the SIMS (Standard Information Management System) event data to its Medicare enrollment and Medical Evidence form information. Use of the SIMS information, collected directly and regularly from the dialysis units, has reduced the number of duplicate, reported new ESRD patients in 2000 and 2001 (see page ix in the Introduction, and page 183 in Appendix A, for further detail on SIMS). Determining the number of prevalent patients receiving ESRD treatment is also a complex task. Through claims for services, the Medicare population can be carefully tracked in the ESRD system. Because non-Medicare patients, however, cannot be followed in this way, they must frequently be given a standard three-year grace period from the time of ESRD incidence before being classified as lost-to-followup. Because these patients may regain renal function or discontinue dialysis prior to the three-year anniversary, the USRDS often reports a higher number of patients under treatment than does the CMS Facility Survey. Once non-Medicare patients complete their EGHP period they become eligible for Medicare, and can be tracked through claims data. But be-

CHAPTER HIGHLIGHTS

- **Figure 2.2** Growth in incident rates per million population has slowed significantly, with the annual percent change less than one percent in 2000 and 2001.
- **Figure 2.9** Counts of incident patients with diabetes have continued to rise, but not as sharply in recent years, and the rate of growth in incident rates of diabetic ESRD has also slowed. Incident rates for patients with a primary diagnosis of glomerulonephritis have declined slightly since the mid-1990s.
- **Figure 2.17** Prevalent counts and rates for diabetics continue to rise, although the rate of increase has declined.
- **Figure 2.22** By 2030, almost 300,000 diabetics are projected to enter ESRD treatment, and the prevalent diabetic population under treatment in that year may be as large as 1.3 million patients.
cause the health plans of Medicare HMO patients do not submit claims to Medicare, the modality of patients covered by these plans is unknown. Here again, then, we can use the SIMS data to create a more complete record of both non-Medicare and Medicare HMO patient status, resolving duplicate patients and more completely ascertaining patient modalities. Incident rates of ESRD appear to be leveling off, with barely a 1 percent increase from 2000 to 2001—the first time the ESRD program has reached this important milestone. The median age of the overall incident population is now 64.5: 67.1 for whites, 59.4 for blacks, 58.7 for Native Americans, 64.0 for Asians, and 60.6 for Hispanics. Incident rates for patients whose ESRD is caused by glomerulonephritis have begun to decline from their peak in 1995–1996, and rates for diabetes and hypertension have slowed significantly. These findings are clear evidence that efforts to address the progression of chronic kidney disease to ESRD may be paying off. In absolute numbers, however, the ESRD population age 45–64 continues to grow, as the World War II baby boomers enter middle age. Prevalent rates continue to rise, although at a rate of only 2.4 percent between 2000 and 2001. The median age of the prevalent population is now 57.8: 58.9 for whites, 56.0 for blacks, 57.0 for Native Americans, 58.2 for Asians, and 56.3 for Hispanics. Absolute growth in the population age 45–64 continues in an almost linear fashion, while that of patients age 20–44 appears to be peaking. Rates for blacks are the highest by race, but the rate of increase appears to be slowing; prevalent rates for Hispanics, tracked since 1995, continue to climb but at a slower rate. Finally, rates by primary diagnosis are slowing, but there is no evidence that they have peaked. Given the encouraging trends in the slowing of the rates, but the steady growth in the number of middle-aged and older patients, we developed a Markov model to estimate the number of patients who may be entering and receiving ESRD treatment by the year 2030. In the 2000 ADR we reported projections to 2010, but these short-term trends did not reflect the aging of the baby boomers nor the growth of the Hispanic and Asian populations, in which ESRD rates are high. The aging of the black population is also an important consideration, since its incident and prevalent rates are 3–4 times that of whites. Between 2000 and 2030 the white U.S. population is expected to grow 21 percent and the black population 40 percent; other non-white populations are expected to increase twice their current size. The number of people with diabetes is expected to grow even more dramatically—110 percent for whites, 176 percent for blacks, and 280 percent for people of other races. Reflecting this growth, by 2006 the number of new ESRD patients with diabetes as their primary cause of ESRD will equal the number of patients with other primary diagnoses. Based on these demographic changes in age, race, ethnicity, and diabetic status, the prevalent population with diabetic ESRD is expected to grow to 1.3 million—nearly a ten-fold increase—while the number of new ESRD patients with a primary diagnosis of diabetes is expected to increase seven times, to 300,000 in 2030. These changes in the general population will clearly have a sobering impact on the ESRD program.
In incidence

The overall incident rate of ESRD continues to increase, but the rate of this change has slowed over the past decade (Figure 2.2). Rates in both 2000 and 2001 increased less than one percent over those of the previous year, reaching approximately 334 per million population. Fluctuations in the increase during 1993 and 1994 were caused by irregularities in the reporting procedures used by HCFA (now CMS), and data for 2001 are preliminary, as reporting delays are frequent and it may take up to 18 months to finalize the data.

Since 1978 the median age of the entire incident population has risen almost 20 percent, from 54 to 65, while that of Asian patients has grown from 44 to 64, more than 46 percent (Figure 2.3). These rates of increase were highest in the earlier years of the ESRD program, and slowed during the 1990s, with an overall increase of only 2.2 years (3.5 percent) from 1990 to 2001.

Since the beginning of the ESRD program, patients age 45–64 have accounted for the greatest proportion of the population—36 percent in 2001 (Figure 2.4). Rates of new cases of ESRD, however, have consistently been highest among older patients, with rates among those age 75 and older out-taking those of patients age 65–74 in 1998.

Both the number and the rate of new ESRD cases have remained higher for males than for females, with rates per million population in 2001 reaching 404 and 280, respectively (Figure 2.5).

Incident rates have increased significantly in most areas of the country since 1991 (Figure 2.6). As of 2001, incident rates in 60 percent of the country were at least 230 per million population.

The overall incident rate of ESRD has quadrupled since the program began, from 82 to 334 per million (Figure 2.7). An almost eight-fold increase, however, has occurred among Asian patients, and blacks continue to have the highest incident rates, reaching almost 1,000 per million population in 2001.
The introduction of the new Medical Evidence form in April 1995 allowed tracking of patient ethnicity to begin, and since that time the number of Hispanic patients has grown—35 percent since 1996 (Figure 2.8). During this same period the incident rate for Hispanic patients has grown 7.8 percent, from 437 to 471 per million population, compared to a growth of 15.6 percent among non-Hispanics.

The rate of new cases of ESRD caused by diabetes continues to climb, reaching 148 per million population in 2001—almost double the rate of a decade earlier (Figure 2.9). From 1990 to 2001 rates of ESRD caused by hypertension grew almost 50 percent, while the increase was 11 percent for glomerulonephritis and 21 percent for cystic kidney disease. Glomerulonephritis rates appear to have peaked, however, in the mid-1990s, and declined nearly 12 percent from 1995 to 2001. Rates of diabetes and hypertension also appear to be leveling out.

For Hispanic patients we present data beginning in 1996, the first full year after the April 1995 introduction of the revised Medical Evidence form, which contains more specific questions on race & ethnicity.
Prevalence

Prevalence is defined as the number of existing patients in a group divided by the number in the general population base, and is influenced by the number of new patients (incidence) and the number of deaths. The rate of existing ESRD cases has increased each year since 1980, though the rate of increase has been slowing since the early 1990s (Figure 2.10). In 2001 the prevalent rate reached almost 1,400 patients per million population, a 2.4 percent increase from the previous year.

Since 1978, the median age of the prevalent population has risen 13.5 percent, from 51 to 58 (Figure 2.11). As in the incident population, the greatest increase—41 percent—has occurred among Asian patients, from 41 to 58. Since the early 1990s the median age has remained relatively steady, increasing in the entire population only three years (5.3 percent) since 1990.

As in the incident population, patients age 45–64 account for the greatest proportion of existing patients (Figure 2.12). Prevalent rates, however, have consistently been highest among those age 65–74. While rates for the entire population have increased 86 percent since 1990, growth has been 110 percent for patients age 65–74, and 153 percent for those age 75 and older. Rates for patients age 0–19 and 20–44, in contrast, have grown just 33 and 49 percent.

Both the number and the rate of existing cases of ESRD have remained highest for males, with rates per million in 2001 reaching 1,670 for males and 1,163 for females (Figure 2.13).

Changes in the prevalent rate between 1991 and 2001 (Figure 2.14) mirror those in incident rates during the same period (Figure 2.6). Rates are highest in the Upper Midwest and the southwestern states.

Since 1980 the overall prevalent rate of ESRD has quintupled, from 271 to nearly 1,400 per million population (Figure 2.15). In the Asian population, however, this increase has been almost twelve-fold. And since 1990, rates have nearly doubled among all races. Blacks and Native Ameri-
Since 1996, after the introduction of the new Medical Evidence form allowed patient ethnicity to be tracked, the number of prevalent Hispanic patients has grown 73 percent (Figure 2.16). The prevalent rate for Hispanic patients has grown 43 percent, from 1,290 to 1,841 per million population, compared to 21 percent among non-Hispanics.

The number of existing cases of ESRD caused by diabetes more than tripled between 1990 and 2001, while the rate per million population increased 167 percent, to 491 (Figure 2.17). Rates of ESRD caused by glomerulonephritis, hypertension, and cystic kidney disease increased 55, 76, and 57 percent, respectively.

Growth in the number of prevalent patients appears to have slowed, but there is no evidence that rates have peaked. These steady increases can be attributed to falling mortality rates among ESRD patients.

For Hispanic patients we present data beginning in 1996, the first full year after the April 1995 introduction of the revised Medical Evidence form, which contains more specific questions on race & ethnicity.

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1. **Geographic variations in adjusted prevalent rates (per million population)**
2. **Prevalent counts & adjusted rates, by race**
3. **Prevalent counts & adjusted rates, by ethnicity**
4. **Prevalent counts & adjusted rates, by primary diagnosis**
Projected population growth

The tables and graphs in Figures 2.18–20 help illustrate the growth projected in United States minority populations over the next three decades. While the number of whites, which increased 9 percent between 1990 and 2000, is expected to grow only 21 percent by 2030, the number of blacks is expected to rise 40 percent, up from a 16 percent growth in the 1990s (Figure 2.18). An even greater population increase is projected among people of other races, whose numbers rose 46 percent between 1990 and 2000, and who are expected to see a five-fold growth in population by 2030.

The greatest population increases by age are expected to occur, not surprisingly, in the older age groups (Figure 2.20). The number of black children is projected to rise 16 percent between 2000 and 2030, only slightly higher than the 11 percent growth in the 1990s. The number of blacks age 65 and older, however, which rose only 10–30 percent during the 1990s, is projected to grow between 146 and 178 percent by 2030. Increases are expected to be even greater among people of other races, with the number age 65 and older expected to triple or even quadruple over 2000 levels.

Growth in the diabetic population is expected to parallel these changes (Figure 2.19). The number of whites with diabetes, which grew 36 percent between 1990 and 2000, is expected to double by 2030, and the number of black diabetics to grow 176 percent. The number of diabetics of other races doubled during the 1990s; from 2000 to 2030 this number is expected to quadruple, reaching 2.9 million.

As shown elsewhere in this ADR, rates of ESRD are high in both minority and elderly populations. The projected growth of the minority populations, then, coupled with the rising age of the World War II baby boomers, mean that projections for the next thirty years show a dramatic increase in the number of people needing therapy for ESRD. The population of existing patients whose ESRD is caused by diabetes, for example, which tripled from 1990 to 2000, is expected to grow ten-fold by 2030, to 1.3 million (Figure 2.22). And the number of patients diagnosed each year with ESRD caused by diabetes is expected to grow from 41,000 in 2000 to 300,000 in 2030, a 600 percent increase.

By age, the greatest growth in the ESRD population by 2030 should parallel that in the U.S. as a whole, with the number of patients age 65 and older projected to rise 500–600 percent over 2000 levels.
By 2030, then, the number of patients with ESRD may reach 2.24 million. Almost 60 percent of these patients are expected to be diabetic, half to be age 65 or older, and half to be of races other than white. Given the differences in clinical indicators and in outcomes among these populations, this projected growth clearly has profound implications for the infrastructure of the ESRD program—for the payor system, for staffing patterns, and for the ways in which care is planned and provided for these at-risk populations.

Figure 2.18 U.S. Census Bureau projections.
Figure 2.19 prevalent rates of diabetes in 1980–1998 obtained from National Health Interview Survey (NHIS) data. These data are linearly extrapolated to obtain prevalent rates for 1978–2030, & estimates are then multiplied by census projections to obtain estimated numbers of individuals with diabetes for 1978–2030. Figure 2.20 U.S. Census Bureau projections. Figures 2.21–24 calculated using a discrete time non-stationary Markov model, which is discussed in Appendix A.
Rare diseases

Disease-specific information on the primary causes of ESRD has customarily focused on broad categories such as diabetes, glomerulonephritis, and hypertension. Many of the less common causes of ESRD are often overlooked, but they too play an important role in the etiology of ESRD.

IgA nephropathy/Berger’s disease and IgM nephropathy are inflammations in the kidney that are associated with the accumulation of IgA and IgM antibodies. The number of new ESRD patients identified with these diseases has slowly increased since 1995, when 498 patients were reported, to a 2001 level of 808—a 62 percent growth (Figure 2.25).

Wegener’s granulomatosis is characterized by chronic tissue inflammation and the formation of granulomas. An overall upward trend in the number of patients diagnosed with this disease each year occurred until 1998; since then patient counts have leveled off, and counts for 1999, 2000, and 2001 were 245, 248, and 240, respectively (Figure 2.26).

Systemic lupus erythematosus is an autoimmune disease in which the body produces antibodies to its own proteins. This leads to inflammation, which can result in arthritis, pericarditis, vasculitis, and kidney damage. Until 1998 the number of new ESRD patients with lupus increased steadily, reaching its highest count of 1,081 (Figure 2.27). Since then, the number of patients has remained relatively constant, and now stands at 992—an increase of three and a half times from the number of new ESRD patients with the disease in 1983.

The number of new ESRD patients diagnosed with other secondary glomerulonephritis (vasculitis)—a condition in which the capillary loops of the glomeruli become inflamed—rose steadily from 1982 to 1998 (Figure 2.28). Counts then leveled off, and in 2001 were more than three times higher than in 1982.
Polycystic kidney disease is an inherited disease typified by multiple cysts within the kidney. Yearly counts of new ESRD patients with this disease have generally risen every year between 1982 and 2001, going from a yearly count of 1,023 to double that (2,171) in 2001 (Figure 2.29).

Alport’s syndrome is an inherited condition characterized by kidney damage, deafness, and hematuria. Yearly counts of new ESRD patients diagnosed with Alport’s or other hereditary or familial diseases increased 61 percent (113 to 182) between 1994 and 1995 (Figure 2.30). Since then, patient counts have not followed a predictable pattern, and have remained relatively steady overall.

Multiple myeloma is a cancer in which abnormal plasma cells multiply at a high rate, releasing proteins that damage the kidneys. Yearly counts of new patients whose ESRD is caused by this disease or by light chain nephropathy have increased steadily since 1982 (Figure 2.31). The number of patients in 2001 (1,139) was more than five times higher than in 1982. The rapid increase in multiple myeloma cases during the mid-1990s may reflect better overall survival, with more patients progressing to ESRD.

AIDS is a disease of epidemic proportions, acquired immunodeficiency syndrome (AIDS) is caused by the human immunodeficiency virus, which destroys the body’s immune system. The number of new patients whose ESRD is caused by AIDS has remained relatively steady since 1995, when 949 patients were reported; 830 were reported in 2001 (Figure 2.32). These findings are in contrast to the steady increase of HIV/AIDS in the general population; the use of protease inhibitors, which have been associated with a marked improvement in survival, may also be helping reduce the likelihood of ESRD.
ESRD network populations

Between 1991 and 2001, the number of new patients with diabetes as the primary cause of ESRD more than doubled in almost every ESRD network (Figure 2.33). This change ranged from 95 percent in Network 1 to 152 percent in Network 9. Growth in the number of patients with hypertension as the primary cause of ESRD ranged from 26 percent in Network 1 to 99 percent in Network 18 (Figure 2.34). Among patients with glomerulonephritis, the highest increase of 57 percent occurred in Network 6, while in Network 7 the number of patients actually decreased (Figure 2.35).

The mean age of both incident and prevalent ESRD patients is highest in renal networks located in the Upper Midwest and in New England (Figure 2.36). Between the upper and lower quintiles, the mean age of incident patients varies more than six years. The prevalent population is younger, and within it the overall difference between quintiles is slightly smaller, at two and a half years.

Among the ESRD networks, incident rates for dialysis patients in 2001 range from a low of 213 per million population in Network 16 to a high of 396 in Network 13 (Table 2.a). Prevalent rates for dialysis patients span an even greater range, from 610 in Network 16 to 1,329 in Network 6 (Table 2.b). And the rate for existing transplant patients ranges from 331 in Network 14 to 493 in Network 11 (Table 2.c).

The proportion of existing patients with diabetes ranges from 37 to 51 percent. In Network 15, consisting of Arizona, Colorado, Nevada, New Mexico, Utah, and Wyoming, the proportion of patients with diabetes is high across all patient populations, with more than 51 percent of all dialysis patients, and 28 percent of prevalent transplant patients, carrying a diagnosis of the disease.

The racial and ethnic distribution of ESRD patients varies widely, not surpris-
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### Table 2a - Incident dialysis patients, 2001

### Table 2b - Point prevalent dialysis patients, 2001

### Table 2c - Point prevalent transplant patients, 2001

### Table 2d - ESRD networks

- **Network 1** Connecticut, Massachusetts, Maine, New Hampshire, Rhode Island, Vermont
- **Network 2** New York
- **Network 3** New Jersey, Puerto Rico, Virgin Islands
- **Network 4** Delaware, Pennsylvania
- **Network 5** Maryland, Virginia, Washington D.C., West Virginia
- **Network 6** Georgia, North Carolina, South Carolina
- **Network 7** Florida
- **Network 8** Alabama, Mississippi, Tennessee
- **Network 9** Indiana, Kentucky, Ohio
- **Network 10** Illinois
- **Network 11** Michigan, Minnesota, North Dakota, South Dakota, Wisconsin
- **Network 12** Iowa, Kansas, Missouri, Nebraska
- **Network 13** Arkansas, Louisiana, Oklahoma
- **Network 14** Texas
- **Network 15** Arizona, Colorado, Nevada, New Mexico, Utah, Wyoming
- **Network 16** Alaska, Idaho, Montana, Oregon, Washington
- **Network 17** American Samoa, northern California, Guam, Hawaii
- **Network 18** Southern California
INTRODUCTION  ■  Figure 2.1  Calculated using a revised methodology that includes data from CMS’s Standard Information Management Systems, USRDS data show incident and transplant counts that are comparable to those of the CMS Annual Facility Survey, though USRDS counts of prevalent patients are slightly higher. INCIDENCE  ■  Figure 2.2  Growth in incident rates per million population has slowed significantly, with the annual percent change less than one percent in 2000 and 2001. ■  Figure 2.3  The overall median age of the incident population is 64.5–67.1 in whites, 59.4 in blacks, 64 in Asians, 58.7 in Native Americans, and 60.6 in Hispanics. ■  Figure 2.4  Since 1980 the steepest rise in incident counts has occurred among patients age 45–64. Incident rates, in contrast, have risen most sharply for patients age 65 and older. ■  Figure 2.7 Incident rates for blacks and Asians have stabilized since the late 1990s. ■  Figure 2.8  Incident rates among Hispanics are 45 percent higher than among non-Hispanics. ■  Figure 2.9  Counts of incident patients with diabetes have continued to rise, but not as sharply in recent years, and the rate of growth in incident rates of diabetic ESRD has also slowed. Incident rates for patients with a primary diagnosis of glomerulonephritis have declined slightly since the mid-1990s. PREVALENCE  ■  Figure 2.10 While prevalent rates have continued to climb, the rate of increase slowed to less than 3 percent in 2000 and 2001. ■  Figure 2.11  The median age of prevalent patients is 57.8. ■  Figure 2.12 Prevalent counts for patients age 45–64 have risen linearly since 1983, while the rate of growth in the population age 20–44 has slowed. Prevalent rates per million population continue to grow, although at a slower rate than in the early 1990s. ■  Figure 2.17 Prevalent counts and rates for diabetics continue to rise, although the rate of increase has declined. PROJECTED POPULATION GROWTH  ■  Figures 2.18–20 Projections of the U.S. population to the year 2030 show the number of blacks increasing almost 40 percent over the population in 2000, the white population growing 21 percent, and other racial groups more than doubling. Growth in the diabetic population is projected to be more than 110 percent for whites, 176 percent for blacks, and 280 percent for people of other races. ■  Figure 2.22 Projections based on the Markov model show that by 2006 the number of incident patients with diabetes as their primary cause of renal failure will equal the combined population of patients with all other primary diagnoses. By 2030, almost 300,000 diabetics are projected to enter ESRD treatment. In the prevalent population, the number of patients with diabetic ESRD will equal that of patients with other primary diagnoses by 2017, and by 2030 the prevalent diabetic population under treatment may be as large as 1.3 million patients. RARE DISEASES  ■  Figures 2.25–32 Incident counts of patients with Wegener’s granulomatosis, lupus erythematosus, secondary glomerulonephritis, and polycystic kidney disease have been relatively flat since 1998. Incident counts for patients with multiple myeloma and light chain nephropathy continue to climb, which may reflect longer survival under chemotherapy. The number of patients with AIDS who reach ESRD has been stable since 1996. ESRD NETWORK POPULATIONS  ■  Figure 2.33 Over the last ten years the population of diabetics has doubled in most ESRD networks, with increases of more than 140 percent occurring in Networks 7, 8, and 9.

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<td>Overall value for all pts</td>
<td>223.1</td>
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<td>313.3</td>
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<tr>
<td>Missing HSA/state: pts dropped</td>
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<td>10,827</td>
<td>8,030</td>
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