

 **USRDS**  
United States  
Renal Data System

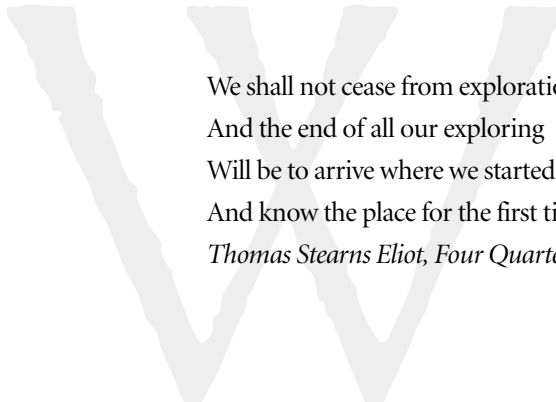
# 2000 Annual Data Report

Atlas  
of End-Stage  
Renal Disease  
in the  
United States

National Institutes of Health  
National Institute of Diabetes  
and Digestive and Kidney Diseases  
Division of Kidney, Urologic,  
and Hematologic Diseases

This 12th annual report of the United States Renal Data System is produced by the USRDS Coordinating Center, operated under NIH contract N01-DK-9-2343 by the Minneapolis Medical Research Foundation.





We shall not cease from exploration  
And the end of all our exploring  
Will be to arrive where we started  
And know the place for the first time.  
*Thomas Stearns Eliot, Four Quartets*



# Contents

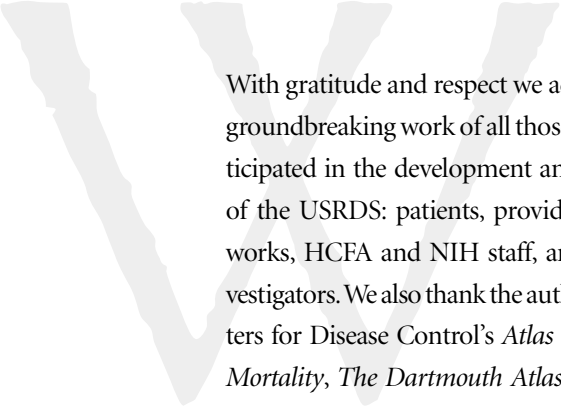
vii	Acknowledgements
ix	Introduction
15	Précis · A summary of the United States ESRD program
37	One · Incidence & prevalence
55	Two · Patient characteristics
69	Three · Treatment modalities
77	Four · Clinical indicators of care
85	Five · Morbidity & hospitalization
97	Six · Pediatric ESRD
115	Seven · Transplantation
127	Eight · Survival, mortality, & causes of death
143	Nine · Preventive health care measures
149	Ten · Provider characteristics
163	Eleven · Economic costs of ESRD
177	Twelve · International comparisons
183	APPENDICES
186	A · Analytical methods
209	B · ESRD Network definitions
210	C · Bibliography
224	D · Glossary
228	E · USRDS staff & co-investigators
230	F · USRDS products & services
241	REFERENCE TABLES

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Publications based upon USRDS data reported here or supplied upon request must include this citation and the following notice:

The data reported here have been supplied by the United States Renal Data System (USRDS). The interpretation and reporting of these data are the responsibility of the author(s) and in no way should be seen as an official policy or interpretation of the U.S. Government.



With gratitude and respect we acknowledge the groundbreaking work of all those who have participated in the development and continuation of the USRDS: patients, providers, ESRD networks, HCFA and NIH staff, and previous investigators. We also thank the authors of the Centers for Disease Control's *Atlas of United States Mortality*, *The Dartmouth Atlas of Health Care 1999*, and the National Cancer Institute's *Atlas of Cancer Mortality in the United States*; each of these innovative volumes has advanced patient care by furthering knowledge not only of disease patterns across the country, but of methods for the geographic display of epidemiological information.





# INTRODUCTION

The United States  
Renal Data System

## WHAT'S NEW

The recent structure of the United States Renal Data System (USRDS) has been marked by significant change. In 1999 the USRDS was divided into a Coordinating Center (CC) and four Special Studies Centers (SSCs). The new contracts for the CC and the Cardiovascular SSC were awarded to the Minneapolis Medical Research Foundation in Minneapolis, Minnesota, and the University of Iowa received the contract for the Economic Special Studies Center (contracts for the Rehabilitation and Nutrition SSCs were not yet awarded as this book went to press). The CC and SSCs continue to be operated under the direction of the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) at the National Institutes of Health (NIH). Figure i.1 details the administration of the USRDS grants, and the integration of activities by the NIH.

The new CC and Cardiovascular SSC contractors are associated with the Hennepin County Medical Center and the University of Minnesota. Figures i.3–5 depict the organizational structure of the USRDS and the teams of co-investigators.

The other central change in the work of the USRDS is already clear to readers familiar with previous Annual Data Reports: as detailed in the *Précis*, we have altered the focus, format, and appearance of the report, hoping to reach even more readers in the renal community, and to provide the most comprehensive information possible on patients with end-stage renal disease.

This 2000 ADR presents data on ESRD patients through 1998, the most recent year for which complete data is available.

## USRDS WEBSITE: [WWW.USRDS.ORG](http://WWW.USRDS.ORG)

Users of the USRDS website can access PDF files of the printed ADR, *Reference Tables*, and

*Researcher's Guide*, download aggregate data and USRDS slides for use in their own analyses and presentations, and correspond with USRDS staff.

## THE USRDS DATABASE

Most data sets used by the USRDS are provided by HCFA. In addition to the complete data of the ESRD Renal Beneficiary Utilization Systems/Program Management and Medical Information System (REBUS/PMMIS) and the Annual Facility Survey, HCFA supplies data from the ESRD networks, data on Medicare beneficiaries, and Medicare Part A and B claims data. The USRDS also obtains data from the United Network for Organ Sharing (UNOS) and from the National Surveillance of Dialysis-Associated Diseases in the United States, compiled by the Centers for Disease Control and Prevention (CDC). The structure of the USRDS database is illustrated in Figure i.2, and detailed descriptions of the database itself and of the methods used to work with and analyze the data are provided in Appendix A.

## MEDICARE & NON-MEDICARE PATIENTS

Since the introduction of the new HCFA Medical Evidence Form (2728) on April 1, 1995, HCFA, the USRDS, and UNOS have been tracking both Medicare-eligible and non-Medicare ESRD patients, and have identified more than 300,000 new patients with ESRD. The amount of data available on these patients, however, differs widely. Patients for whom Medicare is the primary payor are tracked extensively by HCFA, which maintains detailed information on patient modality, hospitalizations, and associated events. For patients with Medicare as the secondary payor, in contrast, as well as for HMO patients in Medicare risk programs, HCFA receives only limited event data. Patients receiving no care through the Medicare system are still included in the HCFA database, but for these patients information is available only from the Medical Evidence

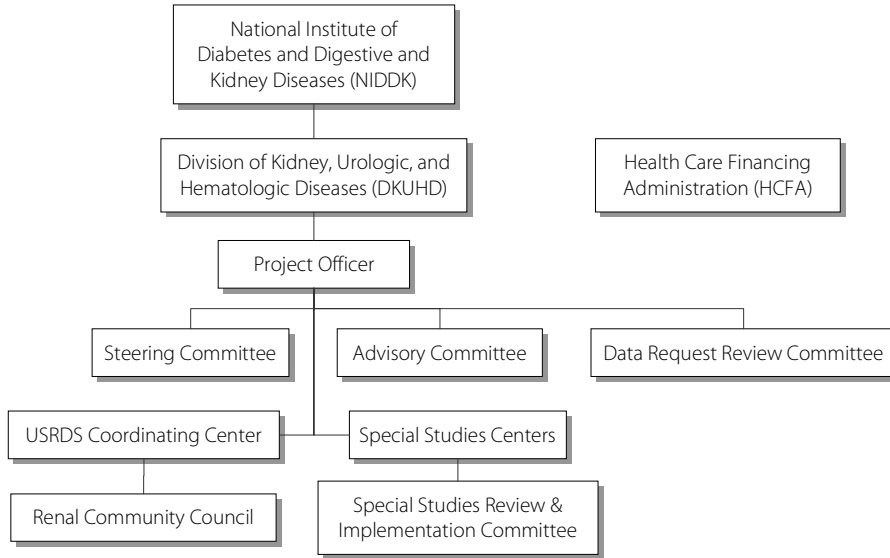


Figure i.1  
**Administrative oversight of the USRDS**

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Table i.1  
**USRDS contacts**

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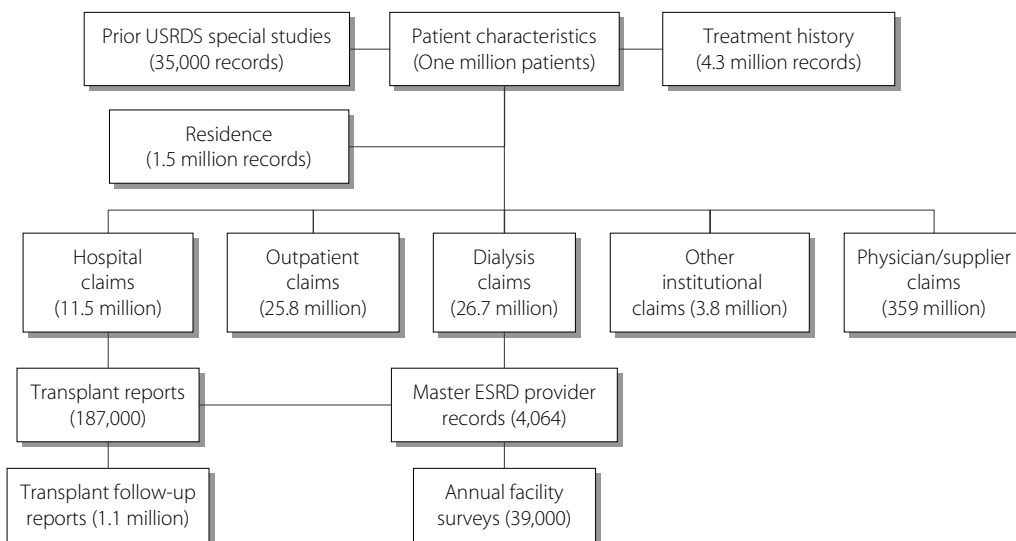


Figure i.2  
**Structure of the USRDS database with counts of patient & facility records as of January 2000**

More information on this database, as well as a detailed description of analytical methods, is provided in Appendix A.

Figure i.3  
**Departmental organization of  
 the Coordinating Center**

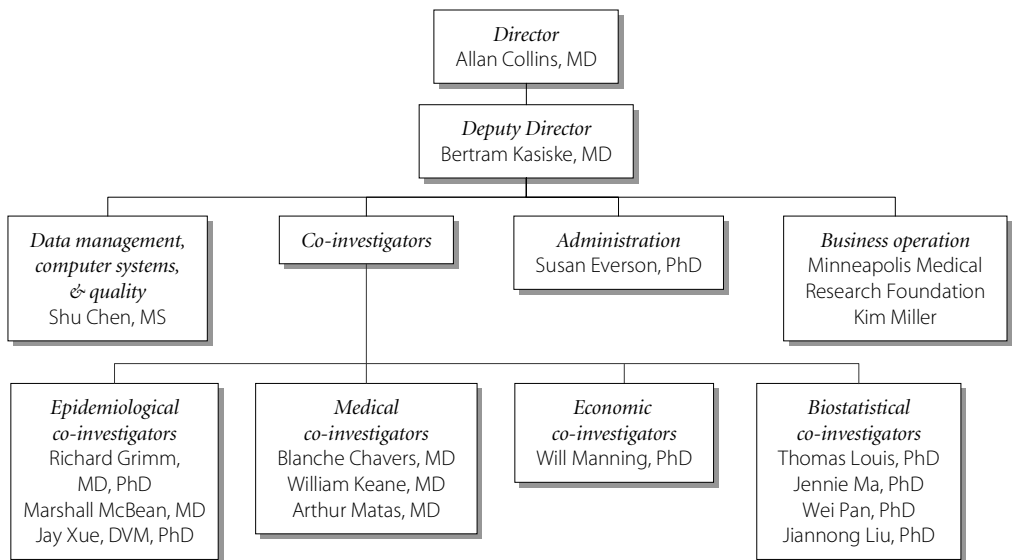


Figure i.4  
**Departmental organization of  
 the Cardiovascular Special  
 Studies Center**

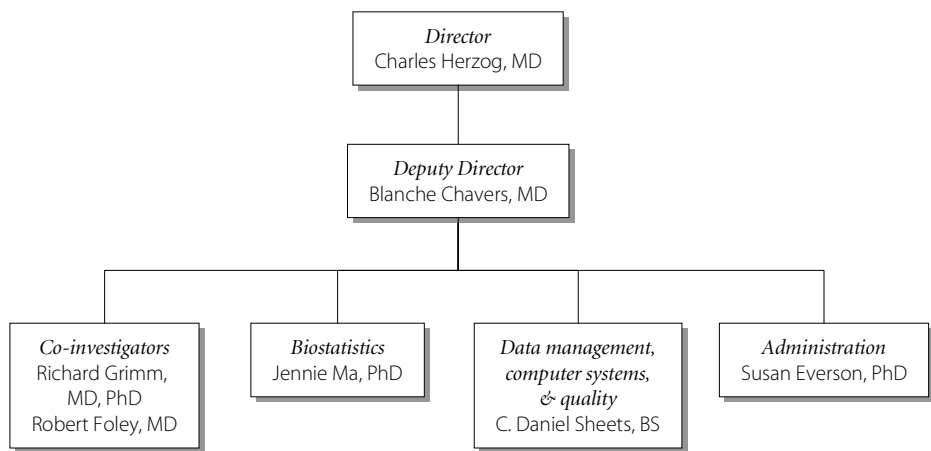
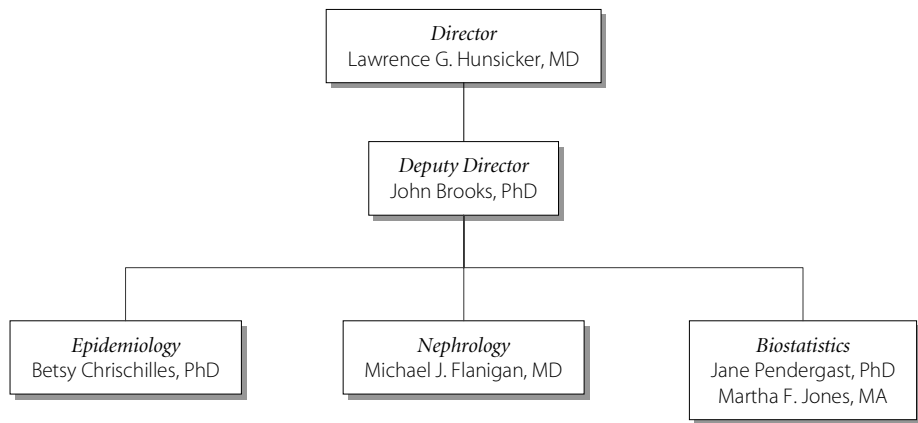


Figure i.5  
**Departmental organization of  
 the Economic Special Studies  
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**National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK)**

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Wei Pan, PhD  
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Table i.2  
**Key personnel of the USRDS**

2728 form, the Death Notification Form (2746), and UNOS transplant forms.

Difficulties in tracking patients as they become eligible for Medicare have been an ongoing challenge for HCFA, the networks, and the USRDS. In this ADR we have carefully defined the differences between Medicare and non-Medicare patients (see discussion in Appendix A), and indicated the populations used for the analyses in each chapter. A more complete reconciliation of Medicare and non-Medicare patients will be possible in the future, as HCFA, the ESRD networks, and

the dialysis providers begin using the new SIMS, REMIS, and VISION software packages (developed by HCFA) to manage patient information.

**USRDS OVERSIGHT COMMITTEES**

Recent changes to the USRDS have also included a restructuring of the oversight committees. Lawrence Agodoa, MD (Project Officer) and Camille Jones, MD (Deputy Project Officer) continue to provide direct oversight of the CC and SSCs, and members of HCFA, the networks, and the renal community provide crucial input and feedback through their committee participation.

The Steering Committee functions as the governing body of the USRDS, and is responsible for the operations of the CC and SSCs. It works under the direction of the Project Officer, and includes representatives from HCFA, the NIH, the CC, and each of the SSCs. Its responsibilities include coordination between the centers, study design, project tracking, data management and validation, assurance of data availability for researchers and government officials, and oversight of Annual Data Report production.

The Data Management Advisory Committee (DMAC), which has been inactive for the last several years, has been re-activated, and includes members from HCFA, Network Forum representatives, database technical staff, and others appointed by the Project Officer. DMAC will address the accuracy and completeness of the data provided to the USRDS CC, and work to ensure the timely fulfillment of data requests made to the USRDS.

The newly formed Annual Data Report Committee (ADRC) will review the data sections of previous ADRs, proposals for expansion of future ADRs, and ideas for expanded data availability on the USRDS website.

Also new, the Information Systems Committee (ISC) will review planned hardware requirements, systems configuration, documentation, and performance, and will evaluate new technologies that may enhance the structure, function, and management of the database.

The Medical Advisory Board will suggest topics for possible investigation, and discuss appropri-

ate analytical methods.

The Scientific Review Group (SRG) has been created to provide initial evaluation of studies proposed by the CC and the SSCs.

The Special Studies Review & Implementation Committee (SSRIC) serves as the operations committee for SSC proposals and for support of CC projects. It is a collaboration of members from HCFA, the ESRD networks, and the providers.

The Data Request Review Committee (DRRC) reviews data requests that will require more than two hours of staff time at the CC or SSCs to fulfill, and makes recommendations to the Project Officer based on the types of data sets requested by researchers and the ways in which the CC can improve the availability of data.

The Renal Community Council (RCC), with 30 professional, scientific, and advocacy groups interested in ESRD, serves as a significant liaison between the USRDS and the ESRD community.

## NOTE

The following materials could not have been produced without the extraordinary work of members of the ESRD community and the dedicated efforts of the USRDS staff and investigators. Feedback on the ADR, *Reference Tables*, and other work of the USRDS is welcomed, and all comments and requests are reviewed by the Director, Deputy Director, and staff in order to provide the best possible responses, improve future materials, and ensure a strong working relationship between the USRDS and clinicians, researchers, patients, and others involved in ESRD care.