

# ANNOUNCEMENTS

## REPORT OF THE END-STAGE RENAL DISEASE DATA ADVISORY COMMITTEE 1991 END-STAGE RENAL DISEASE DATA ADVISORY COMMITTEE

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### Introduction

The charter of the End-Stage Renal Disease Data Advisory Committee as approved by Secretary of Health and Human Services, Louis W. Sullivan, M.D., defines the function of this Committee as follows: "The End-Stage Renal Disease Data Advisory Committee shall provide advice to the Secretary in the Department's formulation of policies and procedures relevant to the management of the Department's data collection and analysis efforts on End-Stage Renal Disease (ESRD). To this end, the Committee will consider and discuss ongoing and planned studies in this area and provide advice to the Secretary regarding their overall integration and coordination. In so doing, the Committee will provide advice to the Secretary regarding relevant biomedical research studies funded by the NIDDK, including the outcomes of experimental therapies for ESRD, and relevant studies funded by the HCFA on economic/cost-effectiveness/reimbursement issues related to ESRD." On this basis, the Committee received testimony from the following 12 organizations: Institute of Medicine (IOM), Renal Physicians Association (RPA), American Society of Nephrology (ASN), Urban Institute, Scientific Advisory Committee of the U.S. Renal Data Systems (USRDS), United Network for Organ Sharing (UNOS), Agency for Health Care Policy and Research (AHCPR), Health Resources and Services Administration (HRSA), National Kidney and Urological Data Advisory Board (NKUDAB), National Kidney Foundation (NKF) Interagency Coordinating Committee on Data Related Activities, and the Centers for Disease Control (CDC) and came up with the following recommendations:

- Congress appropriate sufficient funds to ensure the implementation of the committee's recommendations.

### Research Studies:

- a National Institutes of Health dialysis contract research program be initiated. In addition, the National Institute of Diabetes and Digestive and Kidney Disease (NIDDK), in concert with the Health Care Financing Administration (HCFA), should continue to support definitive research studies to assess the adequacy of dialysis care received by ESRD patients.
- the Department of Health and Human Services (DHHS) support a broad range of studies to examine the relationship between reimbursement levels and quality of dialysis care as well as the adequacy of dialysis training for nephrologists.
- the DHHS encourage the study of ethical issues related to ESRD (e.g., living wills and transplantation rates in minority populations).
- the DHHS encourage the study of the means to prevent ESRD by focusing on the cause and effect relationships

between hypertension, diabetes, polycystic kidney disease, diet, and ESRD. The HCFA should provide data and data analysis in support of this effort.

- the DHHS coordinate the efforts of the United Network for Organ Sharing (UNOS), United States Renal Data System (USRDS), National Kidney Foundation, and HCFA to develop a national strategy (e.g., studies and national education programs) aimed at increasing the number of donor kidneys available for transplantation.
- the Agency for Health Care Policy and Research (AHCPR), the NIH, the Centers for Disease Control, private industry, and nonprofit organizations fund additional special USRDS research studies.

**Data Collection and Dissemination:**

- the HCFA modify its ESRD data collection instruments to identify data related to the Hispanic population within the HCFA/USRDS database.
- the DHHS direct the HCFA and the AHCPR to use the HCFA/USRDS data in the development of quality of care standards and quality assessment systems.
- the DHHS ensure the widest possible dissemination of its data to potential researchers.
- the DHHS ensure that the methods of transplant data collection by the HCFA, UNOS, and USRDS are complimentary, not duplicative.

In addition, based on the recommendation made by the ESRD Data Advisory Committee, the NIDDK and the HCFA will continue to cosponsor the USRDS contract.

### **IgA NEPHROPATHY INTERNATIONAL SYMPOSIUM**

The sixth International Symposium on IgA nephropathy will be held in Adelaide, Australia February 28–March 1, 1993. The program will consist of invited lectures, free communications (oral) and round table discussions. The Annual Scientific Meeting of the Australian and New Zealand Society of Nephrology follows the symposium (March 2–4, 1993). Secretariat: Drs. A.R. Clarkson and A.J. Woodroffe, Renal Unit Royal Adelaide Hospital, North Terrace, Adelaide S.A. 5000 Phone 08 224 5203; FAX: 08 224 0291.

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