

History of UM-KECC

In 1984, Friedrich K. Port M.D., M.S., of the University of Michigan became director of the Michigan Kidney Registry (MKR), the leading state-level registry of End-Stage Renal Disease (ESRD) patients. Robert A. Wolfe, Ph.D., also from the University of Michigan, participated in many of the MKR research studies. At about the same time, Philip J. Held, Ph.D. was conducting economic and health policy research related to ESRD at The Urban Institute in Washington, D.C. using Medicare claims data. In 1987, these researchers collaborated to win an NIH/NIDDK contract for a national ESRD Registry. The result was the U.S. Renal Data System (USRDS). The first USRDS Coordinating Center (1988-1993) was located at the Urban Institute with Philip Held and Friedrich Port as directors, Robert Wolfe as Director of Biostatistics, and Randall L. Webb as Director of Information Systems. In 1993 the second USRDS contract was awarded to the same team, but at the University of Michigan, and UM-KECC was formed.

The Michigan Kidney Registry had its offices at 315 W. Huron St. in suite 340, now occupied by Harley Davidson. The Medical School did not have on-campus space available in 1993, so the USRDS moved into suite 220-240. The Michigan Kidney Registry continued until 1994. Six Urban Institute staff moved to Ann Arbor with the USRDS, and Randall Webb and Marc Turenne are still at UM-KECC. David Dickinson, Greg Levine, and Diane Steffick (all now at Arbor Research) also are former Urban Institute employees, although they did not work on the original USRDS contract.

UM-KECC originally was part of the Nephrology Division of the Department of Internal Medicine and later moved to the Biostatistics Department of the School of Public Health. Faculty and students from Nephrology and Biostatistics continued to collaborate closely on UM-KECC projects.

From 1988 to 1993, UM-KECC produced more than 220 papers, presentations, and abstracts, including 11 *USRDS Annual Data Reports*, each containing about 200 pages of text with tables and figures and 400 pages of reference tables. UM-KECC also carried out eight Special Studies during this period. These studies gathered data from national random samples of ESRD patients, with 2000-5000 subjects per study. Data collection was carried out by the ESRD Networks and dialysis facilities.

To support this work, UM-KECC developed the USRDS database, a comprehensive ESRD patient and facility database, drawn primarily from Medicare data. In order to support studies by researchers outside the USRDS, UM-KECC developed a comprehensive set of Standard Analysis Files (SAFs) containing most of the data in the USRDS database. In 1998, more than 260 CDs of SAF data were distributed under the USRDS contract. Also in 1998, UM-KECC responded to more than 800 data requests to the USRDS.

A major UM-KECC innovation in 1995 was the Dialysis Facility Reports (DFR), originally called Unit Specific Reports. Reports were produced for all of the 3000+ dialysis facilities in the U.S. and were distributed by the ESRD Networks. The DFRs have been produced every year since 1995, funded by the Centers for Medicare and Medicaid Services (CMS) after 1999. The DFRs include detailed information about the characteristics of the facility and of its patients and mortality, hospitalization, and transplant measures adjusted for the characteristics of the patients treated by the dialysis facility. For 2007, each DFR has 18 pages of text and tables and almost 5000 dialysis facilities receive a DFR.

An archival copy of the final USRDS web site from the UM-KECC era is available at www.sph.umich.edu/kecc/usrds/index.htm

In 1996, Philip Held formed University Renal Research and Education Association (URREA) as a private non-profit research organization. In 2006, URREA became [Arbor Research Collaborative for Health](#) (Arbor Research). Friedrich Port became President of Arbor Research in 2002. Arbor Research is housed

in the same building as UM-KECC, and the two organizations collaborate closely on many projects, usually through subcontract arrangements. Friedrich Port and Robert Wolfe succeeded Philip Held as Director of UM-KECC.

In 1999, the USRDS Coordinating Center Contract was awarded to The Minneapolis Medical Research Foundation and was re-awarded in 2006. The structure and content of the USRDS database, the SAFs, and the *Annual Data Report* Reference Tables are largely unchanged from those developed by UM-KECC. No USRDS Special Studies have been completed since 1999.

Starting in 1999, CMS contracted with the University of Michigan for continued production of the Dialysis Facility Reports. To support these reports, UM-KECC has continued to maintain a comprehensive database of ESRD patients, expanding on its design of the USRDS database. This database also supports the PPS contract, other CMS contracts at UM-KECC and Arbor Research, and the SRTR contract (see below).

In 2000, faculty from the Department of Health Management and Policy (HMP) began a collaboration with UM-KECC on a new CMS contract for “Design, Development, and Implementation of an Improved Medicare Outpatient End Stage Renal Disease Prospective Payment System (ESRD PPS)”. This work continued under subsequent contracts led by Richard Hirth, Ph.D., from HMP, and will continue at least through 2008. A Report to Congress was prepared by CMS in 2007 based heavily on the PPS work at UM-KECC. Legislation implementing a bundled PPS system for ESRD appears likely.

Also in 2000, Arbor Research, in collaboration with UM-KECC, was awarded the HRSA contract for the [Scientific Registry of Transplant Recipients \(SRTR\)](#), the national organ transplant registry. The University of Michigan is a subcontractor to Arbor Research on the SRTR. Robert Merion, M.D., of the Department of Surgery, directs the UM subcontract at UM-KECC.

Dr. Merion also directs the data coordinating centers for two large studies of living organ donors funded by NIH. The A2ALL project studies living liver donors, and the RELIVE project studies living kidney and lung lobe donors. These studies will provide much-needed information about middle- and long-term outcomes for living organ donors. Most of the staff for these projects are located at UM-KECC.

Rajiv Saran, M.D., from the Nephrology Division, joined UM-KECC in 2002. Dr. Saran directs a study of chronic kidney disease (pre-ESRD) patients, with emphasis on the interaction between renal and cardiac disease. In 2006, Dr. Saran was awarded a grant from CDC to develop surveillance methods for chronic kidney disease, collaborating with a similar grant to John Hopkins University. Dr. Saran also participates in a number of other UM-KECC and Arbor Research studies.