The Registry attracts European Researcher
From Christoph Wanner, ERA-EDTA Registry Chairman

Since 1964 the ERA-EDTA Registry collects data on renal replacement therapy (RRT) and at present 52 national or regional registries in 30 countries in Europe and bordering the Mediterranean Sea are contributing. Today, a huge data treasure has accumulated at the Department of Medical Informatics of the Academic Medical Center in Amsterdam, The Netherlands. So far, focus was often on important questions describing RRT across Europe, and recently de Jager et al. have dissected cardiovascular and non-cardiovascular mortality rates, their ratio, relative excess and differences across Europe (JAMA 2009).

Now, the time has come to dig deeper to places were patients with rare diseases became numerous. Researchers from all over Europe start to find their way to Amsterdam in order to discover some of the hidden jewels. The Registry Committee (D. Ansell, C. Combe, L. Garneata, F. Jarraya, P. Ravani, R. Saracho, F. Schaefer, S. Schön, E. Verrina, C. Wanner, and ex-officio G. London) has reviewed several written research requests and agreed to support applications from:

- O. Gross, Germany “European Alport Registry joint analysis”
- J. Harambat, France “Treatment strategies and outcomes of paediatric renal transplantation in Europe”
- V. Stel “Incidence, prevalence and progression of CKD stage 4 in Europe” – joined with SysKID EU FP 7

Finally, it’s a great pleasure to report that the new business plan for the next 4 year period has received Council approval recently.

The EVEREST Study: what influences the worldwide variation in RRT incidence and modality mix?
From Fergus J. Caskey for the EVEREST Study group

The EVEREST study – Explaining Variation in Epidemiology of RRT through Expert opinion Secondary data sources and Trend analysis – is an international collaborative project involving nephrologists, epidemiologists and health economists in different countries aiming to determine the medical and non-medical factors that are independently associated with renal replacement therapy (RRT) incidence, dialysis modality mix and patient survival on dialysis.

In 2008-2009, data were collected for 46 of the 51 countries with known national or regional renal registries across the world. Three sources were used:
- Experts: National experts on renal service provision provided information on the organisation of health care systems and renal services and reimbursement of dialysis facilities and physicians.
- Secondary data sources: The WHO Health For All and OECD databases provided information on macroeconomic factors (national wealth and health care spending), health care resources, and population health (life expectancy, ischaemic heart disease rates, diabetes rates etc).
- Renal registries: These provided data on trends in RRT incidence (including rates of diabetic nephropathy), modality mix and survival on RRT.

Across the 46 countries (general population covered 1.25 billion), incidence of RRT ranged from 12-455 (median 130) per million population. Three analyses have now been undertaken – RRT incidence, rates of home dialysis and survival on dialysis – with manuscripts at different stages of development; a fourth analysis of change in RRT incidence over time is ongoing.

The striking finding in all analyses has been the greater influence of macroeconomic and renal service organisational factors rather than general population age and health status factors.

For example, considering the worldwide variation in RRT incidence, Human Development Index, Gross Domestic Product per capita, % Gross Domestic Product spent on healthcare and dialysis facility reimbursement rate relative to Gross Domestic Product independently predicted RRT incidence. A prognostic model with RRT incidence as the outcome variable was able to explain 50-70% of the variation in RRT incidence between countries.
International collaboration with the EVEREST Study has been fantastic and the study group would once again like to thank the renal registries and national experts around the world who have kindly provided data to the study.

SysKID
From Vianda Stel, ERA-EDTA Registry Epidemiologist

What is SysKID?
SysKID, which stands for “Systems Biology towards Novel Chronic Kidney Disease Diagnosis and Treatment”, is a large-scale integrating European research project that aims at understanding chronic kidney disease (CKD) in the context of diabetes and hypertension. It will focus on the early stages of CKD and aim at identifying better strategies for prevention of complications as well as at novel diagnosis and therapy options to improve patients’ quality of life.

Why SysKID?
As far as we know about ten percent of the general population within Europe (circa 50 million people) is affected by the early stages of CKD. In these early stages, the disease typically triggers cardiovascular complications and bone metabolism disorders. Moreover, in Europe the prevalence of diabetes has been increasing rapidly in the last years. As a consequence, the number of patients with CKD and cardiovascular complications will increase. When CKD progresses it makes patients dependent on dialysis and, eventually, kidney transplantation. Therefore, new diagnostic and prognostic markers capable of detecting subjects at risk for renal disease and identification of patients at risk for progression are needed.

SysKID partners
The SysKID consortium consists of 25 research groups from 15 countries, including clinicians, statisticians, epidemiologists, molecular researchers and bioinformaticians from universities, small- and medium-sized enterprises as well as industry partners.

Epidemiological studies within SysKID
From the ERA-EDTA Registry Vianda Stel and Kitty Jager as well as a PhD student will collaborate with other project partners in the SysKID epidemiological studies. One aim will be to provide more insight into the number of patients suffering from the early stages of CKD within Europe and to examine which patients will further progress and who will not. Another aim is to make an inventory of ongoing European studies on early stages of CKD.

Budget and time schedule
The project that has started on January 1, 2010 and is scheduled for five years, is driven by a European Union grant of EUR 11.8 million from Framework Programme 7 and a total project volume of close to EUR 16 million.

Website
More information about SysKID can be found at www.syskid.eu.

This project is supported through European Union’s FP7, Grant agreement number HEALTH-F2-2009-241544.

The ERA-EDTA Registry will make an inventory of ongoing European studies on CKD stage 1, 2, 3, and 4. Therefore, we kindly ask you to contact Vianda Stel (v.s.stel@amc.uva.nl) if you are working on such a study. Thank you for your kind assistance.

UK Renal Registry and new data collection in CKD5
From David Ansell, UK Renal Registry Director

The UK Renal Registry is now collecting data electronically on patients with advanced chronic kidney disease (CKD) who are not receiving renal replacement therapy (RRT). A database of 1,986 patients reaching CKD stage 5 (an incident cohort) at seven UK renal centres has been established. This database has been used to describe the differences in demographic and clinical features between patients reaching CKD stage 5 (not on RRT) and those commencing RRT at the same renal centres. Several abstracts describing some of these novel analyses are shown at this ERA-EDTA conference. The database is also being used to study the longer term outcome of patients after reaching CKD stage 5 including the rate of progression to RRT and factors affecting the probability of survival. These analyses are ongoing and are being led by Dr Daniel Ford, a research specialist registrar at the UK Renal Registry, partially supported by a grant from the Edith Murphy foundation through Kidney Research UK.

ERA-EDTA Registry Activities
during the XLVII ERA-EDTA Congress, Munich, Germany (June 25-28, 2010)

Friday, June 25 - 13.30 - 17.30 – Meeting for national and regional Registries
Saturday, June 26 - 8.00 - 9.30 - ERA-EDTA Registry Symposium