



Note from the Leaving Chairman From Carmine Zoccali, ERA-EDTA Registry Chairman

Six years ago when I was nominated by the Council Chairman of the ERA EDTA Registry, I tried to envisage how I could help the Registry consolidate and grow. My predecessor, Dr. Douglas Briggs, had made a tantalizing effort for bringing back to life the Registry after the 1999 collapse. Thanks to him and Dr. Raymond Krediet arrangements were made for the management of the Registry by a team at the Department of Medical Informatics of the University of Amsterdam. The team was composed by young, motivated, competent epidemiologists and information technology experts and was led by an effective managing director, Dr. Kitty Jager. In 2003 the reborn Registry was a solid federation of registries and the first papers were being published. In this scenario I felt that the best way to help the Registry was to contribute to shape its mission for the challenges that the changing world of nephrology and health care systems in Europe demanded at that time. With some naïveté, I envisaged the activities being extended to the promotion of quality improvement programs, education and special studies in connection with biobanks. These proposals were framed into the QUEST initiative, which stands for Quality European STudies, a name that also means "...an expedition undertaken in medieval romance by a knight in order to perform a prescribed feat". Thanks to the enthusiastic backing of two Presidents, Professors Francesco Locatelli and Jorge B. Cannata-Andía, and the strong, unanimous support of all council members, the initiative was funded by our society. A critical point at that time was that of secure funding also beyond the realm of the ERA-EDTA. With the fundamental backing and collaboration of national and regional registries, the Registry prepared a research proposal for creating an electronic data collection system aimed at feeding continuous quality improvement programs at regional and national level. In 2006 the proposal was awarded by the EU.



Carmine Zoccali

ERA-EDTA President
Gérard M. London
Paris, France

Registry Committee

Carmine Zoccali (Chairman)
Reggio di Calabria, Italy

David Ansell
Bristol, United Kingdom

Christian Combe
Bordeaux, France

Reinhard Kramar
Wels, Austria

Torbjørn Leivestad
Oslo, Norway

Fernando García López
Madrid, Spain

Alison MacLeod
Aberdeen, United Kingdom

Jane Tizard
Bristol, United Kingdom

Enrico Verrina
Genoa, Italy

Christoph Wanner
Würzburg, Germany

Staff

Kitty Jager
Managing Director

Ronald Cornet
Senior IT Specialist

Friedo Dekker
Senior Epidemiologist

Vianda Stel
Epidemiologist

Marlies Noordzij
Epidemiologist

Karlijn van Stralen
Epidemiologist

Anneke Kramer
Medical Information scientist

Annick van den Broek
Datamanager

continued on page 2

Note from the Incoming Chairman From Christoph Wanner, incoming ERA-EDTA Registry Chairman

Following the World Congress of Nephrology 2009 I have the honor to step in the position of chairman of one of the world most renowned dialysis registries which has a tradition of more than 40 years. As Prof. Carmine Zoccali is moving out he is leaving a bar of success high across the sky of European registries. With Kitty Jager, as the solid centre position and chief officer of the Amsterdam based Registry, I personally feel confident to fulfill the requirements the Society expects from the chairman of its Registry. The support of the Society is substantial for the new tasks being threefold: First, the successful work of the previous chairman and the Amsterdam group seeks continuation. Long-lived programs and a new grant (the second in row) from the European Community FP7 framework promises high calibre research in upcoming years. Second, we slowly move towards building up a "Low Clearance Clinic Registry" using focused data collection. Third, the Registry will aim to focus on rare diseases dissecting from the database and collecting from the new predialysis Registry. We will not only use our existing data base, but

also will embark into prospective data collection of rare events (e.g. pregnancy on dialysis). We also aim to liaise with existing small national registries in the field or rare disorders (e.g. calciphylaxia) and rare diseases (e.g. ciliopathies) with the option to support biobanking. The final aim is to provide a solid database for the best specialists and scientists to exploit the phenotypes with adequate methodology, phenotypes which are meticulous collected by clinicians. The time has come were all contributing clinicians can also participate ad personam et nomen in so-called multi-authorship, registry derived, clinical science research projects.



Christoph Wanner

Note from the Leaving Chairman From Carmine Zoccali, ERA-EDTA Registry Chairman

continued from page 1

This NephroQUEST project that is now being carried out is a big challenge, but if successful, as I believe it will be, it may prove to be a turning point for epidemiology research in Europe and allow investigators interested in epidemiology and outcome research the access to a rich, powerful database. The standardization of clinical performance indicators will prove useful to many parties from patients and doctors to health financing bodies. As to education on epidemiology, this may strengthen the Registry's network and produce returns in terms of participation and data sharing, a vital stimulus for a registry purely based on scientific interest and volunteerism like the ERA-EDTA

Registry. In the past years the Registry organized 10 introductory courses on epidemiology in Europe and about 300 nephrologists received education in this discipline. The talent for teaching of Registry staff members and of Friedo Dekker, a senior epidemiologist at the University of Leiden, made these courses very successful. Another lingering issue the Registry considered in the last few years was that of offering coordination for the creation of stage 4 CKD registries in Europe. These registries are now formally recommended by the Kidney Disease: Improving Global Outcomes (KDIGO) initiative. Formulating shared recommendations for regions that plan to start these registries may

serve to prevent the problems of standardization that the ERA-EDTA Registry had in the past and still has.

In concluding my mandate, I can only say that for me the Registry has been a great opportunity for interacting with many outstanding colleagues and a very enriching experience. I learned a lot and truly enjoyed being part of a marvellous team. For this reason I wish to express my gratitude and friendship to the Amsterdam team and to representatives of national and regional registries. I heartily wish the Registry and the new chairman Christoph Wanner all success with their projects.



Last Meeting ERA-EDTA Registry Committee 2006-2009

On March 14 the last meeting of the ERA-EDTA Registry Committee 2006-2009 took place in Brussels. In addition to our chairman Carmine Zoccali who will be succeeded by Christoph Wanner, the following Registry Committee members have reached the end of their term: Reinhard Kramar (Austria), Torbjorn Leivestad (Norway), Alison MacLeod (UK), Fernando Garcia Lopez (Spain) and Jane Tizard (UK). We thank all of them for their valuable efforts in the past years. To replace the members leaving the Committee, four new members will be elected during the Meeting for national and regional registries on May 22.

From left to right: David Ansell, Fernando Garcia Lopez, Vianda Stel, Moniek van de Luijtsgaarden, Reinhard Kramar, Kitty Jager, Christoph Wanner, Marlies Noordzij, Torbjorn Leivestad, Alison Macleod, Christian Combe and Karlijn van Stralen. Carmine Zoccali, Enrico Verrina, and Jane Tizard are missing in this picture.

The 10th Introductory Course on Epidemiology

From March 14-16, 2009 the 10th regular edition of CME Introductory Course on Epidemiology took place in Brussels, Belgium. Special editions of the course took place in Argentina and Greece. In Brussels, thirty-three participants from 13 European countries attended the three-day course which was hosted by local organizer Frederic Collart. During the course ERA-EDTA Registry committee members and epidemiologists from the ERA-EDTA Registry office in Amsterdam provided an introduction in clinical epidemiology by trying to relate epidemiological theory to examples from nephrology.

The lectures focused on topics such as measuring disease occurrence, study designs, bias and confounding, and survival analysis using Kaplan-Meier and Cox-regression techniques. The knowledge gained from lectures was applied during hands-on-sessions, in which the participants performed statistical analyses themselves using SPSS.

Although the course is short it tries to bring across a large quantity of information. Though having already taught more than 300 nephrology researchers the course still seems to fulfil a need. After Brussels another one was given in Mexico-City as a pre-congress course to the SLANH-Congress. The next courses will be held in Bologna, Italy (October 2009) and Vilamoura, Portugal (February 2010).

ERA-EDTA Registry Activities during the World Congress of Nephrology 2009 in Milan, Italy (May 22-26)

Friday, May 22 - 9.00 - 12.00 a.m. - Meeting for national and regional registries

Saturday, May 23 - 8.00 - 9.15 a.m. - ERA-EDTA Registry Symposium