



NephroQUEST **From Carmine Zoccali, ERA-EDTA Registry Chairman**

It is for me a great pleasure seeing the QUEST initiative making important steps forward in fulfilling its mission statement, i.e. promoting quality studies and continuous quality improvement programs (cQIPs) in Europe. Since 2005, the time we started this initiative, the demand for better quality in clinical care by patients and health financing organizations has increased considerably which now makes fulfilling QUEST goals even more compelling. Establishing electronic procedures for data capturing in existing European filing systems is a critical step for the success of NephroQUEST. Data capturing will facilitate enormously data collection by the registries. In this respect the pilot projects that will be started in the next few months in various countries will serve to identify the difficulties and the barriers ahead. Thus, after a long preparatory phase, NephroQUEST is entering into a hot, hands-on, phase. Establishing consensus on the most suitable clinical indicators to adopt in cQIPs is an important achievement and now the adaptation of these indicators for use in children is a good opportunity for bridging adult and paediatric nephrology and adult and paediatric renal registries. In this respect the determination by the ERA-EDTA and ESPN in strengthening the collaboration between these renal registries is of foremost importance for the scientific growth of the same registries. This move will indeed make possible new studies and new analyses across all age groups. I believe that in the medium term, a 5 years time-frame, we will witness the products of NephroQUEST becoming a fundamental support for decision-making for clinical nephrologists, clinical investigators, patients and health organizations alike. Ongoing efforts by the regional and national registries that entered QUEST and by the ERA-EDTA Registry will produce the rewarding results we all expect.



Carmine Zoccali

NephroQUEST Progress Report 2009 **From Kitty Jager, NephroQUEST Project Manager** **Ronald Cornet, NephroQUEST IT Manager** **and Carmine Zoccali, ERA-EDTA Registry Chairman**

After the last ERA-EDTA Congress in Stockholm all partners continued working on the project. The first so-called deliverable to produce was the adaptation of the NephroQUEST list of standardized clinical performance indicators (which was developed for adult dialysis patients) for



Kitty Jager

NephroQUEST Associated partners

ERA-EDTA (United Kingdom)
Academisch Medisch Centrum (The Netherlands)
Agence de la biomédecine (France)
Česká Nefrologická Společnost (Czech Republic)
Consiglio Nazionale delle Ricerche - Istituto di Biomedicina (CNR-IBIM) (Italy)
Klinični Center Ljubljana (Slovenia)
Nederlandstalige Belgische Vereniging voor Nefrologie (Belgium)
Renal Association, UK Renal Registry (United Kingdom)
RENINE (The Netherlands)
Spitalul Clinic de Nefrologie "Dr Carol Davila" (Romania)
Szpital Kliniczny Nr 1 Akademickie Centrum Kliniczne AMG (Poland)
Tartu Ülikool (Estonia)
Türk Nefroloji Denerjisi (Turkey)
Universität zu Köln - QiN (Germany)

NephroQUEST Collaborating partners

Eesti Nefroloogide Selts (Estonia)
Fresenius Medical Care Deutschland (Germany)
Hans Mak Instituut (The Netherlands)
Ministry of Health and Welfare, General Hospital of Athens (Greece)
Nederlandse Federatie voor Nefrologie (The Netherlands)
Società Italiana di Nefrologia (Italy)
Societatea Romana de Nefrologie (Romania)
Société Suisse de Néphrologie (Switzerland)
Stichting Nationaal ICT Instituut in de Zorg (The Netherlands)
Suomen munuaistautirekisteri (Finland)
Svensk Njurmedicinsk Förening (Sweden)

use in children. Our colleagues involved in the Registry of the European Society for Paediatric Nephrology (ESPN) completed the work and thereafter a new database for the collection of paediatric data could be produced. In the meantime this work within the ESPN/ERA-EDTA Registry has resulted in the further addition of the data of 11 paediatric renal registries. Within the project on automated data extraction from electronic patient records two important documents were produced. The first one describes the legal context and the standardization aspects of data safety, whereas the second one outlines the implementation aspects of secure data transfer. Together, these documents provide the basis for the pilot projects on data extraction which are currently being prepared in five different countries.

continued on page 2

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continued from page 1

To address the crucial issue of data quality another document was made outlining the standard operating procedures (SOPs) for the capture of data at renal centres which will be complemented by SOPs for processing of data transferred to renal registries. The pilot projects in the different countries will now need to demonstrate the feasibility of this approach. We expect that the tools and applications emerging from this will ease future data processing and transfer. The pilot work needs subcontracting and has been put out to tender.

Very recently we started a number of other projects including one to further increase the quality of data collected. The first meeting on the issue took place last February in the office of the UK Renal Registry in Bristol where our colleagues from the French Agence de la Biomédecine put forward a research proposal for the comparison of the quality of data collected in different ways. The second project deals with the development of effective techniques for reporting clinical performance indicators. This project will be led by the University of Cologne

based QiN project. Finally, there will be a study on existing and potential quality improvement programmes using clinical performance indicators in nephrology. We were satisfied that in the past year the first NephroQUEST interim report was accepted by the Executive Agency for Health and Consumers (EAHC). Nevertheless, this progress report shows that in the remaining project period there is still quite some work to be done.

The Extension of the Romanian Renal Registry

From Liliana Garneata – Registry Director

One of the aims of NephroQUEST is to assist new and existing renal registries to further develop towards high-quality renal registries. One of the seven registries participating in this part of the project is the Romanian Renal Registry (RRR). The RRR was founded already in 1994 as a structure of the Ministry of Health, administered by “Dr Carol Davila” Teaching Hospital of Nephrology (SCD) and guided by a National Committee, including members from the Ministry of Health, the Insurance House, the Romanian Society of Nephrology, and an SCD representative. Its initial aim was to collect individual data on RRT patients to allow a well-balanced development of health care facilities and to assess the need for resources. The data are monthly collected with web-based data entry at each centre and are used for double-checking with the National Insurance House. As the reimbursement to the centres is made according to the completeness of reported data, the RRR is covering 100% of the country both in terms of centres and of patient population (85 centres by the end of 2008). Before the start of the NephroQUEST project only a core dataset was collected: identification number, gender,

date of birth, RRT method, events (change in RRT method, recovery of renal function, death, transfer, lost to follow-up) and only aggregated data were reported to ERA-EDTA Registry. At that time the RRR staff included four technicians, supervised by two nephrologists who worked as advisors on a voluntary basis. Financial support from the NephroQUEST allowed the part-time employment of the clinician nephrologists. A statistician is still needed. Since the start of the project the staff in the renal centres were trained and the databases in each centre were re-evaluated to include the cause of death. In addition, we started to make annual registry reports based on individual patient data starting with the year 2006. As a result we now participate in the ERA-EDTA Registry with individual patient data. Furthermore, under the auspices of the NephroQUEST project, new software was created allowing web transmission of the data. This new software, which is to be implemented this month, is user-friendly, includes clinical performance indicators and co-morbidity data, allows for self-control of the collected data by the centres and also allows automated data extraction from



Liliana Garneata

the centres' databases. RRR's objective for the end of the project was to also monitor the quality of RRT care. This now seems to be feasible given the progress we have recently made.

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