



Registered Charity No. 1060134

ERA-EDTA Registry
Newsletter 20, May 2012
www.era-edta-reg.org

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The Registry continues the Transition

By **Kitty J. Jager (ERA-EDTA Registry Managing Director)**
and **Christoph Wanner (ERA-EDTA Registry Chairman)**

In recent years the ERA-EDTA Registry has extended beyond its classic mission of 'studying the epidemiology of renal diseases' by growing into an attractive instrument for education and research. The ERA-EDTA and ESPN/ERA-EDTA Registries now work together on datasets of children transitioning into adults. Facilitating research on rare diseases has resulted in papers for which a large database like ours is a prerequisite. Both registries are grateful for what individual countries and regions are dedicating to these large databases. Over the past two years authors



from all across Europe have contributed to more than sixty scientific papers.

In the future education will continue to be a main focus of the Registry. Introductory courses on epidemiology will be supplemented by NDT junior reviewer training in critical appraisal, the first course to be held this June. Several researchers visited Amsterdam to work together on epidemiology data. Both nephrologists working in adult and paediatric nephrology will continue to be very welcome for research fellowships at the new *ERA-EDTA Clinical Epidemiology Research and Learning Centre* in the Academic Medical Center in Amsterdam. This new initiative will further assist the growing importance of epidemiology in the nephrology field.

Finally, besides research performed on the Registry's database and under the umbrella of special studies, the ERA-EDTA Registry participates in the EC funded SysKID consortium and it contributes to the ERA-EDTA European Renal Best Practice Group. The recently started EQUAL Study in stage 4 CKD patients in five European countries will form the basis for a future registry including predialysis patients.

Picture: ERA-EDTA Registry team during the PhD defence by Anneke Kramer. From left to right: Vianda Stel, Marlies Noordzij, Friedo Dekker, Moniek van de Luitgaarden, Karlijn van Stralen, Anneke Kramer, Christoph Wanner and Kitty Jager.

A new web-based search tool for a new PRD coding system

By **Keith Simpson (Chair QUEST Coding & Definitions Working Group)** and **Kitty Jager (ERA-EDTA Registry Managing Director)**

The current ERA-EDTA coding system for primary renal diseases leading to end-stage renal failure is almost 40 years old. As a result of medical progress in diagnosis of kidney disease nephrologists felt that the current options for recording primary renal disease were incomplete and inflexible. For this reason the ERA-EDTA Coding & Definitions group including nephrologists, epidemiologists, medical informaticians and coding specialists created a new list of 273 codes for primary renal diseases to replace the former one which included only 65 codes. The new coding system does not limit itself to diseases resulting in end-stage renal failure but encompasses more renal disorders. In addition, all the diseases are linked to the relevant SNOMED codes and from there to ICD-10 codes. This will prevent the need for mapping to ICD-10 at the national level in countries where ICD-10 codes are needed for reimbursement purposes. As the number of codes quadrupled we expect that future users will need some time to adapt to the system.

To facilitate the working with the new system the ERA-EDTA Registry Office has developed a web-based search tool. This tool enables nephrologists to look up the new PRD code for a particular patient. This can be done by entering text, for example a part of the name of the disease. The system will then come up with a list of options from which the nephrologist may choose. The presentation of each code includes an information button comprising any related links to the webpages of the Online Mendelian Inheritance in Man (OMIM) database, criteria for diagnosis, the old ERA-EDTA PRD code and the SNOMED and ICD-10 codes and terms.



Update on the ESPN/ERA-EDTA Registry

By Karlijn van Stralen (ESPN/ERA-EDTA Registry coordinator)

Over the last year the ESPN/ERA-EDTA Registry developed and implemented a new internet-based data collection tool that allows countries to participate in the Registry directly with standardized data. Moreover, five papers have been published in high-ranking medical journals and another five papers have been submitted. Finally, in the past year four clinicians from all over Europe visited the

AMC to perform research projects using Registry data, underlining the international and collaborative character of the Registry, which offers unique clinical research opportunities to junior (paediatric) nephrologists from all over Europe.

During the congress there will be a lecture during the ERA-EDTA Registry symposium on policies and practices of paediat-

ric kidney transplantation across Europe. Second, during the paediatric nephrology session (Friday May 25, 11.45 a.m.) data will be presented on post-transplant disease recurrence and graft loss which is still a major problem in paediatric nephrology. Finally, there will be a poster on Saturday on adult height after childhood onset RRT in Europe.

Do you know an unpublished study in CKD patients not on RRT?

By Vianda Stel (ERA-EDTA Registry epidemiologist)

The wide variation in definitions for incidence, prevalence and progression of chronic kidney disease (CKD) complicates attempts to compare the burden of CKD between European countries. For any useful comparison an analysis using the same definitions is needed.

The aim of our study is to compare the incidence, prevalence and progression of CKD in all stages of CKD in patients not on RRT within Europe. This study combines work within two European projects, of which one (SysKID, www.syskid.eu) focuses on CKD stage 1, 2 and 3 and the other (QUEST) on CKD stage 4. We will use existing data. After an investigation of the available data and the different definitions used, we will attempt to harmonize the definitions and ask for a rerun of the analyses using common definitions.

FRIENDLY REQUEST

We kindly ask you to contact Katharina Brück (k.brueck@amc.uva.nl), if you know a study satisfying the following criteria:

- unpublished study performed in Europe
- data on (e)GFR and/or albuminuria
- patients with CKD (stage 1-5) not on RRT
- general population based or follow-up study
- total population or specific patient subgroup (e.g. age group, sex, diabetes)

We would very much appreciate your help!

Vianda Stel, Katharina Brück, Christoph Wanner, Wim van Biesen, Charlie Tomson, Giovanni Tripepi, Carmine Zoccali and Kitty Jager on behalf of SysKID and QUEST researchers.

Congenital anomalies of the Kidney and Urinary tract; not only a paediatric problem

By Karlijn van Stralen (ESPN/ERA-EDTA Registry coordinator) and Elke Wühl (paediatric nephrologist, Heidelberg, Germany)

During the ERA-EDTA Registry symposium (Friday May 25, 8.00 a.m.), Dr. Elke Wühl, will present the results on Congenital Anomalies of the Kidney and Urinary Tract (CAKUT). CAKUT constitute the most common cause of renal replacement therapy (RRT) in children, but the incidence of hypo/dysplastic kidneys progressing to RRT beyond childhood and the global outcomes of RRT due to CAKUT are unknown. Using data from the ERA-EDTA Registry, we showed that in over 2/3 of the patients, RRT was initiated only in adult life, and half of them even started after the age of 32 years. RRT was initiated earlier for patients with isolated renal dysplasia than with renal hypoplasia and with associated uropathies. Patient survival on RRT was slightly better for CAKUT patients when compared to age- and gender matched non-CAKUT controls, probably due to lower cardiovascular mortality. Patients with neurogenic bladder-related disease were more likely to die and less likely to receive a transplant than patients with other CAKUT. This shows that in patients with congenitally reduced nephron mass, the progression of chronic kidney disease due to ongoing loss of remnant nephrons is probably a life-long process.



Elke Wühl

ERA-EDTA Registry Activities during the ERA-EDTA Congress in Paris, May 24-27, 2012

Friday, May 25, 08.00-09.30 a.m.
ERA-EDTA Registry Symposium

Programme:

- 1) Introduction on the Registry 2012.
Christoph Wanner, Würzburg, Germany
- 2) European nephrologists' experience with the decision not to start RRT.
Moniek van de Luijngaarden, Amsterdam, The Netherlands
- 3) EQUAL study - an international study in Stage 4 CKD.
Kitty Jager, Amsterdam, The Netherlands
- 4) Policies and practices of paediatric kidney transplantation across Europe.
Jérôme Harambat, Bordeaux, France
- 5) Pregnancy in dialysis patients - a systematic review.
Marlies Noordzij, Amsterdam, The Netherlands
- 6) Timing and outcome of RRT in patients with congenital malformations of the kidney and the urinary tract.
Elke Wühl, Heidelberg, Germany

Registry publications

Since our last newsletter (November 2011), more than 10 papers with Registry authorship have been published. A complete list of these publications can be found on our website: www.era-edta-reg.org.