

A note from the leaving chairman

By Christoph Wanner

After successful 6 years, Carmine Zoccali handed over the chairmanship of the ERA-EDTA Registry in 2009. Since then it was a challenge to work with a team of extraordinary epidemiologists, informaticians and PhD students, headed by managing director Dr. Kitty Jager. Ultimately, with a visit of Ziad Massy (Paris), the transition phase of the ERA-EDTA Registry chairmanship has started.

It was always a great pleasure to discuss and develop the annual work plans with the Amsterdam team and communicate to the ERA-EDTA Council. The Registry's major tasks can be divided among three pillars: (1) the Annual Report, (2) epidemiological education and (3) the special studies and research projects.

- (1) Most time and daily work is going into the analyses of data from all registries across Europe. Results are distributed through Registry reports presented at the ERA-EDTA congresses, in publications, and through the website. Major areas of work include the focus on rare diseases, the formation of a coding and definitions working group and the development of new primary renal disease codes. Another exceptional collaboration emerged in 2010 with the European Society of Paediatric Nephrology. A grant from the ERA-EDTA boosted a group of paediatric and talented researchers to unearth many hidden treasures from their database.
- (2) The ERA-EDTA Registry extended its activities to education in epidemiology. In October 2014 it organized the 27th Introductory Course on Epidemiology and by now over 800 nephrologists and researchers from all over Europe are educated.

- (3) Visiting researchers can come to the Clinical Epidemiology Learning and Research Centre at the ERA-EDTA Registry to conduct research under guidance of the Registry staff. They can stay from several weeks to up to 6 months and are supported by grants from the fellowship program of the society. Further study projects that have been successfully concluded or are ongoing include the EVEREST study, the SysKID consortium, the project on CKD prevalence in Europe, and the EQUAL study (www.equal-study.org). This study in CKD patients above 65 years with an eGFR ≤ 20 ml/min/1.73m² investigates the transition phase into dialysis. Also, recently EURODOPPS has been initiated with the group of DOPPS researchers from Ann Arbor.

The 6 years with the Registry culminated last year with The Registry's 50th anniversary. This was celebrated with the national and regional renal registries in Europe at the 51st Annual Congress of the ERA-EDTA. It was a pleasure to see so many friends and colleagues which support this unique network, dedicated to expand the knowledge of RRT care in Europe.



SARS-AFRAN-ERA-EDTA Renal Registry Workshop

By Razeen Davids and Marlies Noordzij

On World Kidney Day, 12 March 2015, a Renal Registry Workshop for African nephrologists was held in Cape Town, South Africa. This workshop was initiated by Razeen Davids and was organized in conjunction with the South African Renal Society (SARS), the African Association of Nephrology (AFRAN) and the ERA-EDTA. The aim of the workshop was to teach African nephrologists how to start a renal registry in their own country

and how to improve the quality of their registry if one already exists. This was achieved through lectures on various topics including data quality, data security, benchmarking, and basic principles of epidemiology. The faculty consisted of ERA-EDTA Registry staff members and representatives from the renal registries in France and the UK. The workshop was attended by 30 nephrologists and nephrology researchers from 11 African countries and was well-received by the participants. We hope that this successful workshop will be a first step in the development of a renal registry for the African continent.





Leading European Nephrology

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Why do girls with end-stage renal disease wait longer for transplantation than boys?

By Julien Hogan, Cécile Couchoud, Marjolein Bonthuis, Jaap W. Groothoff, Kitty J. Jager, Franz Schaefer and Karlijn J. Van Stralen for the ESPN/ERA-EDTA Registry

Renal transplantation is recognized as the treatment of choice for end-stage renal disease. Despite the World Health Organization recommendations regarding fair access to transplantation, studies in adults have demonstrated important inequalities between women and men. In both Europe and the United States female gender has been associated with lower access to transplantation, substantially lower registration on the transplant waiting list and a longer time from the start of dialysis to wait listing. Therefore, we aimed to validate this gender inequality in a large paediatric population and to investigate its underlying causes by studying a large cohort of 6454 children treated in the 35 countries participating in the ESPN/ERA-EDTA registry.

We found that girls had a slower access to renal transplantation than boys and demonstrated that this difference was because of a 23% lower probability of receiving a pre-emptive transplantation. Moreover, we found a longer follow-up time of almost one year prior to RRT in boys compared to girls. As the gender difference was most prominent among patients with CAKUT, probably explained by the fact that uropathic CAKUT manifesting in early childhood is more common in boys, we speculated that this might lead to an earlier diagnosis and subsequently to a more timely referral for transplantation work-up in boys than in girls. However, when adjusting for age and cause of renal failure we found no significant gender difference in eGFR at first visit to a specialist, whereas the

lower rate of pre-emptive transplantation in girls persisted. Hence, delayed diagnosis or referral does not fully explain the lower access of girls to pre-emptive transplantation. The other hypothesis that we tested was that the gender difference could be explained by difference in time of progression towards end-stage renal disease. A more rapid progression of renal failure in girls would give less time to prepare them for pre-emptive transplantation. We indeed found a trend towards faster rate of eGFR decline in females.

However, medical factors explained only 70% of the gender-specific difference in pre-emptive transplantation rates. Non-medical factors such as patient motivation and parental and physician attitude towards living donor transplantation may participate in this inequality between genders and need to be studied in detail. Our study should raise awareness for the management of girls with renal diseases and prompt all caregivers to avoid any undue delays in pre-transplant workup.

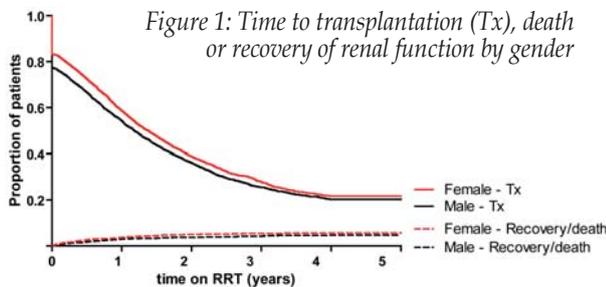


Figure 1: Time to transplantation (Tx), death or recovery of renal function by gender

ERA-EDTA Registry activities during the ERA-EDTA Congress in London, UK

CME 12 Cross-talk in Renal Epidemiology

Thursday May 28th
ExCeL London, Capital Suite 7/12

Co-organized by the UK Renal Registry, the UK Renal Association and the ERA-EDTA Registry

13:15-14:45 pm - **Part 1**

Chairs: Kitty Jager and Bénédicte Stengel

- Selection bias in renal research
Giovanni Luigi Tripepi, Reggio Calabria, Italy
- Understanding and handling missing data
Margaretha Steenkamp, Bristol, UK
- Linkage to create big data sets
Marie Evans, Stockholm, Sweden

15:15-16:45 pm - **Part 2**

Chairs: Fergus Caskey and Dorothea Nitsch

- IV analysis
Friedo Dekker, Leiden, Netherlands
- Propensity scores
Elizabeth Williamson, London, UK
- Time dependent confounding.
MSM, G computation -
Stijn Vansteelandt, Ghent, Belgium

Symposium 4 ERA-EDTA Registry Symposium

Friday May 29th, 8:00 - 9:30 a.m.
ExCeL London, Room S11

- Why do girls with end-stage renal disease wait longer for transplantation than boys?
Julien Hogan, La Plaine Saint-Denis, France
- EURODOPPS - Fergus Caskey, Bristol, UK
- Racial disparities in the access to and outcomes of paediatric RRT
Lidwien Tjaden, Amsterdam, Netherlands



- Trends in the epidemiology of renal replacement therapy
Maria Pippias, Amsterdam, Netherlands
- Stage 4 CKD - first results of the EQUAL study
Moniek van de Luitjgaarden, Amsterdam, Netherlands

Registry Posters

Posters presenting studies performed within the national and regional renal registries can be found in the middle of the poster area opposite the catering area.

ERA-EDTA Registry booth

Please visit our booth in the exhibition hall (C-120) to meet the Registry staff and for questions on educational activities, research collaborations or other registry matters.