



The Registry's 50th anniversary

By Kitty Jager and Christoph Wanner

One year after the birth of ERA-EDTA during its first Congress in Amsterdam in 1964, it was decided to start a renal registry including all European patients on renal replacement therapy (RRT) for end-stage renal disease. The first registry Chairman was the famous Dutch nephrologist Willem Drukker and already one year later, during the second EDTA congress in Newcastle, the first Registry Report was presented. This report included data on 187 transplanted patients and 271 patients treated with haemodialysis in whom mortality after one year was as high as 44%.

Especially in the first years of the Registry's existence dialysis and transplantation were innovative medical treatments and the number of renal centres was relatively small. The European RRT Registry was a unique example of international cooperation, which was followed in the United States, Canada, and Australia-New Zealand. Nowadays renal registries exist in virtually all developed and also in many developing countries.

In the meantime the Registry had moved to Germany and in 1976 it moved to St. Thomas's Hospital in London where it remained until 1999. Since 1971 a paediatric RRT registry had been added to the ERA-EDTA Registry and many papers both on adult and paediatric nephrology were published in this successful period. However, in the 1990s the Registry began to experience difficulties with the computerization of the database and with the fact that the number of renal centres across Europe had increased to almost 4000. Because the Registry nearly collapsed the ERA-EDTA Council decided to move it to the Academic

Medical Center (AMC) in Amsterdam where the Registry made a completely new start in 2000 under the chairmanship of Douglas Briggs.

Nowadays the ERA-EDTA Registry is still based in the AMC. It is a collaborative effort by the registry office and the national and regional renal registries from about 30 countries. The database includes core data on the demography, renal disease, treatment and outcomes of half a million RRT patients. Additional data for specific studies are collected on a regular basis. There is also a close collaboration with the ESPN/ERA-EDTA Registry; the new paediatric registry which started in 2007 and has a separate collection of extensive clinical data. In addition, the ERA-EDTA Registry has extended its activities to education. Since 2004, 25 Introductory Courses on Epidemiology have been organized (see below) and visiting researchers are welcome to conduct specific research projects under the guidance of registry staff in the ERA-EDTA Registry Clinical Epidemiology Learning and Research Centre at the AMC.

This year the Registry celebrates its 50th anniversary; an anniversary that will not pass unnoticed. During this 51th ERA-EDTA Congress in Amsterdam special Registry activities will take place. On May 31 a one-day pre-congress CME entitled "Cross talks in renal epidemiology" is organized in conjunction with the International Seminar on Renal Epidemiology (ISRE) followed by a Registry Symposium on the next day. Finally, the Registry will present its activities in their own booth in the congress exhibition area. We look forward to meeting you here in Amsterdam!



The 25th Introductory Course on Epidemiology

After the first ERA-EDTA CME Introductory Course on Epidemiology was organized in 2004 in Rome, many more followed and more than 750 nephrologists from all over Europe have attended these successful courses. The aim of this epidemiology course is to teach nephrologists and nephrology researchers basic epidemiology principles and to have them practise their new skills in hands-on sessions (exercises, discussions and statistical analysis using SPSS). The knowledge and skills obtained assist participants to improve the quality of their nephrology research.

Ten years after the first course, the 25th edition of the course was organized on March 6 and 7, 2014 in the old city centre of Amsterdam; the home city of the ERA-EDTA Registry. The course was attended by nephrologists and researchers from 10 different countries and was well-received by the participants.

In the future, the Introductory Courses on Epidemiology will keep on being organized spread over Europe.

For an overview of the courses provided and for more information please visit the section educational programme at

www.era-edta.org.





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Renal replacement therapy for rare diseases affecting the kidney: an analysis of the ERA-EDTA Registry

by Elke Wühl, Karlijn J. van Stralen, Franz Schaefer, and Kitty J. Jager for the ERA-EDTA Registry



Six to eight percent of the European population is suffering from a rare disease, i.e. a life-threatening or chronically debilitating condition, affecting less than 1 in 2000 people. More than 80% of rare diseases have a genetic cause and are present

throughout a patient's lifetime. Although the awareness of the special needs of these patients has substantially increased over the last years, information on the overall prevalence of rare diseases within the end-stage renal disease (ESRD) population is limited.

To identify those rare diseases within the ERA-EDTA Registry for which renal replacement therapy (RRT) is being provided, ERA-EDTA primary renal disease codes were mapped with the ORPHANET classification of rare diseases. Data on prevalence and incidence of RRT for ESRD due to 20 identified rare disease entities, both for children and adults, were extracted from the ERA-EDTA Registry including information from 12 countries with 165 million European residents.

From January 2007 to December 2011, 100,745 patients included in the contributing registries in

Europe started RRT, of these 1.5% were younger than 20 years of age. 7,194 patients started RRT for a rare disease, of which 10.6% were children and adolescents. While some diseases were exclusively found in adults (e.g. Fabry disease), primary oxalosis, cystinosis, congenital anomalies of the kidney and urinary tract (CAKUT) and medullary cystic kidney disease affected young patients in up to 50%.

On December 31, 2011, 20,595 patients (12.4% of the total RRT population) were on RRT for ESRD caused by a rare disease. The prevalence of RRT for rare diseases was 32.5 per million age-related population in children and 152.0 in adults. Only 5.8% of these patients were younger than 20 years; however, almost 3 out of 5 children compared to only 1 out of 9 adults on RRT suffered from rare diseases affecting the kidney, with a potentially large number of additional undiagnosed or miscoded cases. CAKUT and focal-segmental glomerulosclerosis were the most prevalent rare disease entities. Comprehensive diagnostic assessment and the application of accurate disease classification systems are essential for improving the identification and management of patients with rare kidney disease.

ERA-EDTA Registry activities during the ERA-EDTA Congress in Amsterdam, The Netherlands

51st ERA-EDTA CONGRESS
AMSTERDAM THE NETHERLANDS MAY 31st JUNE 3rd 2014

CROSS-TALK IN RENAL EPIDEMIOLOGY

Saturday May 31, room: E102

Co-organized by the ERA-EDTA Registry and the International Seminar on Renal Epidemiology (ISRE)

10:30-12:45 PART I: National registry work

- Impact of BMI on ESRD outcomes, *Máthilde Lassalle, Paris, France (REIN)*
- Is higher co-morbidity the explanation for the increased mortality seen in waiting list patients compared to renal transplanted patients? *Vibeke Rømming Sørensen, Copenhagen, Denmark (Danish RR)*
- The Swedish Renal Registry - a source of epidemiological research *Staffan Schön, Jönköping, Sweden (Swedish RR)*
- Factors associated with survival of type 1 diabetes patients on RRT *Jaakko Helve, Helsinki, Finland (Finnish RR)*
- Characteristics and survival of kidney re-transplantation *Beatriz Mahillo, Madrid, Spain (Spanish RR)*
- Measuring what is important to patients - PROMS and PREMS *Fergus Caskey, Bristol, UK (UKRR)*

13:30-16:30 PART II: Guidelines

- Methods for searching the literature: why and how *Evi Nagler, Ghent, Belgium*
- Measuring quality of renal care: patient preference and other things to keep in mind *Sabine Van der Veer, Amsterdam, Netherlands*
- **Research methods**
- Methods in qualitative research: exploring the supportive care needs of haemodialysis patients. *Katherine Bristowe, London, UK*
- Methods to compare the effectiveness of interventions in the post-RCT era *Wolfgang Winkelmayr, Palo Alto, USA*
- Methods to compare cost-effectiveness of interventions *Rachael Morton, Oxford, UK*



ERA-EDTA REGISTRY SYMPOSIUM

Sunday June 1, 11:45 - 13:15 a.m., room: Elicium 1

- Fifty years of ERA-EDTA Registry - an instrument for Research and Education *Kitty Jager, Amsterdam, Netherlands*
- Long term renal transplant outcomes in primary glomerulonephritis *Maria Pippias, Amsterdam, Netherlands*
- Peritoneal dialysis: decreased use and better outcomes? *Moniek van de Luitgaarden, Amsterdam, Netherlands*
- Disturbance of calcium phosphate metabolism in paediatric transplant recipients *Marjolein Bonthuis, Amsterdam, Netherlands*
- Longitudinal association of inflammation markers and endothelial dysfunction markers with left ventricular mass in hypertensive predialysis chronic kidney disease patients *Vianda Stel, Amsterdam, Netherlands*
- The ERA-EDTA Registry - opportunities for future research *Christoph Wanner, Würzburg, Germany*

REGISTRY POSTERS

Posters presenting studies performed within the national and regional renal registries are being presented in the poster area and can be found on the right side of the Poster Help Desk.