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ERA-EDTA Registry
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www.era-edta-reg.org

Looking into the future...

By Christoph Wanner (ERA-EDTA Registry Chairman)

Golden is the color for Istanbul and golden appears the future of the ERA-EDTA Registry. In spring Kitty Jager, director of the Registry, presented the future plans for data collection, education and clinical research to the new Registry Committee members (see photo). The ERA-EDTA Council has approved the plans. In recent years the group of epidemiologists, medical informaticians and PhD students, working in the Amsterdam office of the ERA-EDTA and the ESPN/ERA-EDTA Registries, was joined by 8 visiting researchers, including fellows and adult and pediatric nephrologists from all over Europe. Together with the national and regional registries and the visiting researchers the Registry has successfully worked on more than 100 educational and research projects (see publications at www.era-edta-reg.org). Since 2004, about 700 nephrologists have been trained during the 23 epidemiology courses that took place in 16 countries and last autumn the new ERA-EDTA PRD codes were published as a result of the hard work of the ERA-EDTA Registry Coding & Definitions working group.

In the future the Registry additionally is extending its capacity to so-called 'focused data collections' including clinical variables. This will enrich existing data sets, being able to answer new research questions. Moreover, a new vision has been put forward to progressively build up a low clearance (pre-dialysis) registry. The starting point is the EQUAL study, a prospective cohort study, in which 6 European countries (Germany, Italy, Poland, Sweden, the Netherlands and UK) are included in the first phase. EQUAL has completed its pilot phase with more than 200 patients and is spreading out to approximately 200 centres. The EQUAL investigators study the transition of pre-dialysis patients (eGFR<20ml/min/1.73m2) above 65 years of age into dialysis as well as the patients who remain in conservative care.

Thus, the Registry has enriched its traditional role and established a *Clinical Epidemiology Learning and Research Centre* in Amsterdam. Many of the visionary initiatives under the umbrella of QUEST (Quality European Studies), created by the previous Registry chairman and current Editor of NDT, have fallen on prolific grounds and the golden times of the Registry have just begun.

Picture, from left to right: Vianda Stel, Ivan Rychlik, Anneke Kramer, Karlijn van Stralen, Moniek van de Luijtgaarden, James Heaf, Denis Fouque, Christoph Wanner, Jaap Groothoff, Frederic Collart, Marlies Noordzij, Franz Schaefer, Cecile Couchoud, Staffan Schön, Kitty Jager and Fergus Caskey.

Patients with granulomatosis with polyangiitis and microscopic polyangiitis in the ERA-EDTA Registry

By Zdenka Hruskova and Vladimir Tesar (Prague, Czech Republic)

ANCA-associated vasculitides (AAV), particularly granulomatosis with polyangiitis (GPA, formerly referred to as Wegener's) and microscopic polyangiitis (MPA), are relatively rare but potentially life-threatening autoimmune diseases that have been recognised as the leading cause of rapidly progressive glomerulonephritis. Despite advances in the therapeutic management of AAV, about 20-30% of AAV patients with renal involvement develop end-stage renal disease (ESRD) within 5 years. Data on the prognosis of AAV patients requiring RRT is relatively limited.

In the current study, we aimed to describe the incidence and outcomes of European patients on RRT for ESRD due to AAV. Twelve renal registries providing data to the ERA-EDTA Registry for at least 16 years between 1991 and 2010 participated. A total of 2,371 vasculitis patients (1,650 GPA and 721 MPA) were identified among 195,826 incident RRT patients, representing an incidence of 1.01 per million population (pmp) for GPA (predominating in the northern countries) and 0.44 pmp for MPA (prevailing in the south). Renal transplantation was performed in 360 with GPA (21.8%) and 139 with MPA (19.3%). The 10-year survival probability since day 91 after the start of RRT was 34.2% (95% confidence interval 30.9-37.5%) in GPA and 25.7% (21.5-30.2%) in MPA. We found that adjusted patient survival on RRT, on dialysis and after kidney transplantation did not differ between AAV and non-vasculitis non-diabetic patients. Adjusted graft survival was better in patients with GPA than in non-vasculitis non-diabetic patients.

The epidemiology of treated ESRD due to ADPKD in Europe

By Ron T. Gansevoort, Groningen, The Netherlands

Adult Dominant Polycystic Kidney Disease (ADPKD) is the most common heritable kidney disease, affecting approximately 1 in every 1000 subjects. Most affected subjects show progressive renal function decline and need renal replacement therapy (RRT) between their 50th and 70th year of age. It is generally assumed that this patient group forms around 10% of all subjects who are dependent on dialysis or living with a kidney transplant, but differences in prevalence between regions have been suggested.

Several treatment options have become available to postpone the need for RRT in subjects with renal disease, such as blood pressure control, RAAS inhibition and low protein diets. These treatments have also been tested in ADPKD, generally with disappointing results. However, these studies should be interpreted with caution, since they were not powered to reach definitive conclusions. Furthermore, the included ADPKD patients were often still in the phase of their disease where renal function is relatively stable. In such patients it is not possible to study the renoprotective efficacy of interventions. Therefore, a conclusive answer to the question whether the normal renoprotective regimens are ineffective in ADPKD is lacking. Interestingly, two observational studies suggested that the average age of onset of end-stage renal disease (ESRD) in ADPKD patients increased considerably during the last two decades. This finding has been interpreted as that this patient group has been subjected to effective renoprotective therapies. Unfortunately, also these two latter studies were underpowered, and should therefore be considered as hypothesis generating rather than as proof that indeed renoprotection can be obtained in this patient group. Moreover, the increase in average age at which these patient start RRT could also be due to the fact that during the last decades more elderly have become eligible to enter RRT programs.

Despite the fact that ADPKD is one of the most common causes of ESRD, the epidemiology of treated ESRD due to ADPKD has poorly been studied. Using the ERA-EDTA Registry data a comprehensive overview of the largest epidemiological dataset on ADPKD ever will be given. Attention will be paid to regional differences in prevalence of treated ESRD due to ADPKD, which methods of RRT these patients receive, and method specific mortality data. Most important, data will be provided on the incidence and average age at onset of treated ESRD. In the absence of solid data from randomized controlled trials, we will speculate whether the epidemiological data that will be presented may provide information on the effectiveness of normal renoprotective regimens in ADPKD.

DIAPER: requesting data on pregnancies on dialysis

By Marlies Noordzij (ERA-EDTA Registry epidemiologist)

At the ERA-EDTA Registry we recently started the DIAlysis and Pregnancies in EuRope (DIAPER) study. With this study we aim to estimate the incidence of pregnancies in chronic dialysis patients from 2007-2011 in Europe and to assess which treatment regimens are used in pregnant dialysis patients and which ones are associated with the best outcomes for mother and child.

The data collection has started in many European countries and consists of 2 parts. For the first part, we ask one staff member per dialysis centre to complete 3 short questions (also if the centre did not record any pregnancies). In case one or more pregnancies were recorded, we ask for more detailed data on the(se) patient(s).

We kindly ask your help in the data collection for the DIAPER study. If your centre would like to participate and was not already invited to do so, please contact me at m.noordzij@amc.uva.nl or visit our website (www.era-edta-reg.org) for more information. We would very much appreciate your help!

Marlies Noordzij, Kitty Jager, Enrico Imbasciati, Graham Lipkin and Christoph Wanner.

ERA-EDTA Registry activities during the ERA-EDTA Congress in Istanbul, Turkey (May 18-21, 2013)

Saturday, May 18

• 10:00-13:00 **CME CKD cohorts across Europe** (room Camlica)
- Chronic Kidney Disease in Europe, K. Brück
- German CKD study, K.-U. Eckardt
- EQUAL study, K. Jager
- CKD-REIN, B. Stengel
- The Berlin Initiative Study - a cohort of older adults, E. Schaeffner

• 14:00-17:00 **CME Issues in critical appraisal of observational research** (room Camlica)
- Setting up your study: study questions and study designs, V. Stel
- Threats to validity of study findings: bias and confounding, K. Jager
- Prognosis versus aetiology, F. Dekker
- Interpretation and presentation of study results, B. Siegerink

Sunday, May 19

• 8:45-10:00 **ERA-EDTA Registry Symposium** (room Anadolu)
- Introduction, C. Wanner
- Cardiovascular risk profile in children on RRT, M. Bonthuis
- Rare diseases in the ERA-EDTA Registry, K. Jager
- Vasculitis (granulomatosis with polyangiitis and microscopic polyangiitis), V. Tesar
- Adult Polycystic Kidney Disease, R. Gansevoort
- Dialysis and pregnancies in Europe: the DIAPER study, M. Noordzij