

## Educational activities An update

By Kitty Jager and Marlies Noordzij

### Launch of e-learning course “How to become a reviewer”

In 2012, Professor Carmine Zoccali, who was at that time Editor in chief of Nephrology Dialysis Transplantation (NDT), initiated the first “NDT course for reviewers to-be” together with Friedo Dekker and Kitty Jager. The course included lectures on a variety of clinical research methods and training in the critical appraisal of medical literature. After some face-to-face editions, it was decided to transform the course into an e-learning so that more nephrologists and nephrology researchers could be trained as reviewers. This course will be freely available for all ERA-EDTA members and can be found in the European Nephrology Portal (ENP).

### Introductory Course on Epidemiology in Moscow, Russia

On March 9 and 10 of this year the 31<sup>st</sup> edition of the ERA-EDTA CME Introductory Course on Epidemiology was organized in Moscow, Russia. The course was hosted by Helena Zakharova and Larisa Prikhodina and was well received by the almost 40 participants.



## Update on the EQUAL study

By Nick Chesnaye



The European QUALity study on when to start dialysis, is an ongoing prospective observational cohort study in 65+ CKD stage 4 and 5 patients in six European countries. EQUAL focusses on a combination of patient quality of life, survival, uremic signs and symptoms, nutritional status, and treatment preferences, to provide insight in the benefits and burden of dialysis initiation. The ultimate goal is to determine whether or not, and if so, when, to initiate dialysis in this population. Since its inception in 2012, around 1700 patients have been included, and data on numerous clinical parameters have been collected over the span of 9000 study visits. Recently, it was decided to lengthen the study follow-up duration beyond the intended four years to capture all patient outcomes, vital for the continued success of the study. Presently, an EQUAL biobank containing patient serum and urine samples is underway, which will open up interesting future possibilities for studies in various ‘omics’ fields.

To date, EQUAL has enabled numerous studies in the advanced CKD population, with subjects varying from sex disparities, polypharmacy, quality of life, uremic signs and symptoms, and nutritional status. The latter, recently published by Windahl et al in the Journal of Renal Nutrition [1], evaluated the prevalence and risk factors for protein-energy wasting (PEW) in the EQUAL population, assessed by the 7-point Subjective Global Assessment (SGA) tool. The authors found that most patients had a normal nutritional status, a quarter were moderately malnourished, and less than 1% had severe malnutrition. SGA subscales showed that 21% of patients had experienced recent weight loss, 23% had inadequate food intake and/or gastrointestinal symptoms, 28% had signs of subcutaneous fat loss, and 34% had signs of muscle wasting. Female gender and increased age were significantly associated with an increased risk of PEW, as well as a history of psychiatric disease (i.e. depression/dementia). The authors conclude by highlighting the importance of detecting early signs of PEW in older adults with advanced CKD.

1. Windahl K et al. Prevalence and Risk of Protein-Energy Wasting Assessed by Subjective Global Assessment in Older Adults With Advanced Chronic Kidney Disease: Results From the EQUAL Study. J Ren Nutr 2018



ERA-EDTA President  
**Carmine Zoccali**  
Reggio Calabria, Italy

#### Registry Committee

**Ziad Massy (Chair)**  
Paris, France

**Fergus Caskey**  
Bristol, United Kingdom

**Cécile Couchoud**  
Saint Denis La Plaine,  
France

**Marie Evans**  
Stockholm, Sweden

**Patrik Finne**  
Helsinki, Finland

**Jaap Groothoff**  
Amsterdam, Netherlands

**Jérôme Harambat**  
Bordeaux, France

**James Heaf**  
Copenhagen, Denmark

**Faïçal Jarraya**  
Sfax, Tunisia

**Maurizio Nordio**  
Padua, Italy

**Ivan Rychlik**  
Prague, Czech Republic

#### Staff

**Kitty Jager**  
Managing Director /  
Epidemiologist

**Ronald Cornet**  
Senior IT Specialist

**Vianda Stel**  
Epidemiologist

**Marlies Noordzij**  
Epidemiologist

**Anneke Kramer**  
Medical Information Scientist

**Maria Pippias**  
MD / PhD Student

**Arno Weerstra**  
Data Manager

**Gita Guggenheim**  
Secretary

[www.era-edta-reg.org](http://www.era-edta-reg.org)

# The European EDITH kidney patients survey on treatment modality choice

By Vianda Stel and Rianne de Jong

The EDITH project aims to examine the effect of practice variation in the management of end stage kidney disease (ESKD) and in access to dialysis and kidney transplantation on patient outcomes and costs. The EDITH consortium consists of 10 partners from all over Europe together with collaborating stakeholders including the European Kidney Health Alliance, renal registries, ERA-EDTA, the European Kidney Patients Federation, the French Agence de la Biomédecine and national kidney foundations.

The ERA-EDTA Registry participates in a work package of the EDITH project that will address the epidemiology and costs of different treatment modalities for ESKD. One of the aims of this work package is to examine factors that influence the choice of treatment modalities made by patients

and nephrologists. To this end, the EDITH kidney patient survey on treatment modality choice is currently being distributed among dialysis and kidney transplant patients in almost all European Union Member States and associated countries; the questionnaire for nephrologists will follow. The EDITH kidney patient survey is available in various languages and can be found at [www.era-edta-reg.org](http://www.era-edta-reg.org).

Kidney transplantation provides the greatest longevity and highest quality of life at the lowest costs, but unfortunately remains underutilized. Hence, a significant part of the EDITH kidney patient survey focuses on the barriers and facilitators of receiving a kidney transplant from a living or deceased kidney donor in the different European countries. As a substantial group of patients with ESKD may not be suitable for a kidney transplant, the survey also investigates barriers and facilitators for particular forms of dialysis. Other parts of the survey involve the type of and satisfaction with the information provided on each treatment modality and the extent to which patients were involved in the decision making process. The results are expected to differ across the European countries.

The EDITH project may have an impact on the treatment choices made by patients and doctors and on health care policies, and could help improving the access to dialysis and in particular to kidney transplantation in European countries. See also [www.edith-project.eu](http://www.edith-project.eu).



## ERA-EDTA Registry activities during the 55<sup>th</sup> ERA-EDTA Congress in Copenhagen, Denmark

### Cross-talk in Renal Epidemiology

Thursday 24 May, 9:15-12:00 PM  
Congress Hall A3

- Can we use longitudinal data in survival analyses? - Dorothea Nitsch
- Interaction analyses - Friedo Dekker
- How to validate the predictive value of a biomarker? - Giovanni Tripepi
- Epidemiological study designs and public health impact - Simon Fraser
- Grading evidence - Evi Nagler

### ERA-EDTA Registry Symposium

Saturday May 26, 11:45 AM-13:15 PM  
Auditorium 15

- Trends in the Kidney Donor Risk Index (KDRI) in Europe - Maria Pippias
- The European EDITH kidney patients survey on treatment modality choice - Rianne de Jong
- Nutritional status decline in older adults with advanced Chronic Kidney Disease; results from the EQUAL study - Marie Evans
- European disparities in access to transplantation and graft failure in children - Marjolein Bonthuis

### Posters

Posters presenting studies performed within the national and regional renal registries can be found in the Poster Area of the Bella Center Copenhagen.

### ERA-EDTA Registry booth

Please visit the ERA-EDTA booth in the exhibition hall to meet the Registry staff and for questions on educational activities, research collaborations or other registry matters.

