

# New kids on the block in the ERA-EDTA Registry

The coverage of Europe by the ERA-EDTA Registry keeps growing and currently we are receiving data on renal replacement therapy (RRT) from 49 national and regional registries in 34 countries. Last year, the renal registries

of Cyprus, Lithuania and Switzerland for the first time contributed data to the ERA-EDTA Registry. Below these 3 registries introduce themselves and tell how their registries developed over time.

## CYPRUS

By Dr Kyriakos Ioannou,  
Cyprus Renal Registry representative



With a population of less than one million, Cyprus is one of the smallest countries in the EU. Nephrology services are offered by both public and private hospitals. However, RRT is only provided by 6 public hospitals, and transplantation only by the largest hospital on the island. Each year, approximately 160 patients start dialysis and around 30 receive a transplant. Although each hospital collects its own data, there has never been an attempt to collect and analyse these data in an organized manner.

Collaboration on research projects with ERA-EDTA Registry staff, especially Dr Stel, led to the idea of Cyprus contributing data to the ERA-EDTA Registry. After the first contact in 2014 and it took one year for the 6 hospitals to organize data collection in a uniform manner. In 2015, with the contribution of Dr Pippias who visited Cyprus and helped boost this effort, we provided for the first time data for the 2013 Annual Report. Now, all hospitals regularly provide data to the Cyprus Renal Registry and the ERA-EDTA Registry.

I feel the establishment of the Cyprus Renal Registry will help to guide future policies on RRT provision and CKD prevention in Cyprus and to plan future studies. I feel great gratitude to those staff members of the Registry who helped accomplish this idea and to my Cypriot colleagues who shared this dream and made it a reality.

## LITHUANIA

By Edita Žiginskienė,  
Lithuanian Renal Registry representative



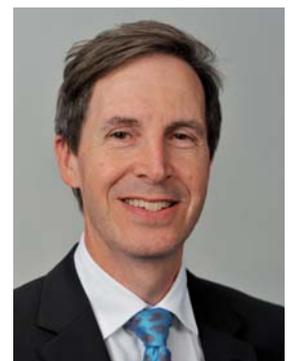
No precise data about patients on RRT in Lithuania were available until 1996 and a renal registry was absent. Starting from 1996, in December of each year all haemodialysis centres were visited by trained doctors and fellows who collected data manually using special paper questionnaires. The data collection was initiated by the Nephrology Clinic of the Lithuanian University of Health Sciences in Kaunas. From 2003, the Lithuanian Nephrology, Dialysis and Transplantation Association (LNDTA) started to guide and support this database. Information about the number of patients and haemodialysis stations, demographics, etiology of renal failure, dialysis quality, blood tests, and medication was obtained. Every data collection was followed by dissemination and discussion of the results within the Lithuanian and Baltic nephrological communities. From 2013, additional data collection was started, including number of RRT centres, patients per centre and the incidence and prevalence of RRT by treatment modality. In 2015, aggregated data on RRT in 2013 were for the first time submitted to the ERA-EDTA Registry. In the same year, collection of detailed data on dialysis patients was legally validated by the Ministry of Health in Lithuania. Each dialysis centre now has to fill in a questionnaire and LNDTA is responsible for the analysis and dissemination of the data. It is planned to include data on transplanted patients to this database in the near future.

## SWITZERLAND

By Patrice Ambühl,  
Swiss Renal Registry representative

The Swiss renal registry quality assessment program (srrqap) was founded in 2006 by the Swiss Society of Nephrology and collected data from dialysis patients exclusively. In the first 6 years, coverage of the Swiss dialysis population was rather low (about 40%) and as a consequence Switzerland was not represented in the ERA-EDTA Registry. In 2012, a new dialysis contract was established, which made data collection mandatory by law, and a percentage from the dialysis tariff became deductible to finance the dialysis registry. These measures allowed reestablishing the srrqap in a more professional manner. First, a user friendly online platform was developed for data entry. Second, a project coordinator was hired to implement the new platform. In 2015, the first data collection for the 2013 census could be accomplished. Data from

3712 patients from 81 centers were reported to the Registry, representing a coverage of 95%. This year, a new online analysis tool was made available to all participating centres, allowing the generation of a customized report of the own patient population, including benchmark comparisons with the entire Swiss dialysis cohort. Ongoing and upcoming projects include the electronic import of laboratory data, establishing a national auditing system, and collection of demographic data from the Swiss transplant population. The goal for 2017 is to contribute individual instead of aggregated patient data to the ERA-EDTA Registry.





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by *Maria Pippias, The Netherlands*

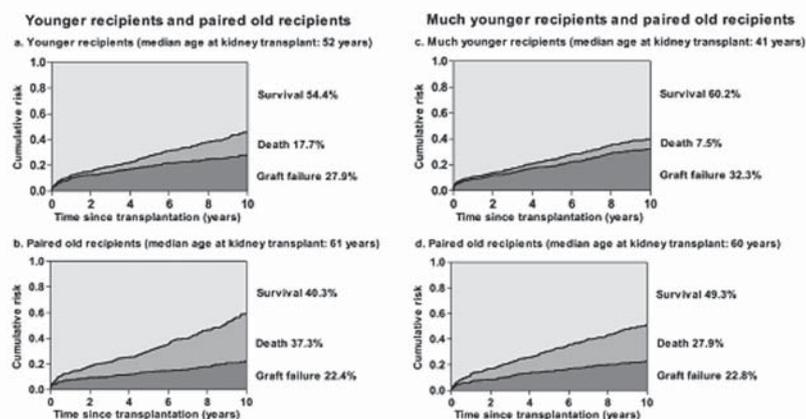
Over the past two decades demand for transplantable organs has resulted in an increased utilisation of older 'marginal' deceased donor kidneys. Subsequently the median age of deceased kidney donors has risen to approximately 55 years old. The outcomes of kidneys transplanted from deceased donors aged  $\geq 55$  years into recipients of differing ages in the current era are lacking. This information could assist transplant organisations when allocating available organs and clinicians when accepting an older deceased donor organ. Using renal and transplant registry data from nine European countries/regions we performed a prospective observational study by means of a paired kidney analysis. Our aim was to determine the survival outcomes of two kidney allografts donated from the same older deceased donor and transplanted into two recipients; a recipient younger than the donor and a recipient of similar age to the donor.

The study consisted of 1,410 adult transplant recipients transplanted between 2000 and 2007 with an allograft from a deceased donor aged 55-70 years. Each donor donated two kidneys; one recipient was either  $\geq 6$  to  $< 13$  ('younger') or  $\geq 13$  years younger ('much younger') and the second paired recipient was of similar age to the donor ('old').

## Encouraging kidney transplant outcomes from older deceased donors: A paired kidney analysis by the ERA-EDTA Registry

Compared to the old recipients the mean number of functioning graft years at 10 years was six months longer in the younger and much younger recipients. Ten-year graft survival was 54% and 60% for the younger and much younger recipients, and 40%-49% for the paired old recipients (see figure). Compared to old recipients, there was a similar risk of death-censored graft failure, but a lower risk of graft failure. Furthermore, there was no difference in estimated glomerular filtration rate at 7 years. These 10-year survival probabilities of older deceased donor kidneys are encouraging and remarkably higher than prior published outcomes. This study highlights the need to re-evaluate transplant outcomes to ensure up-to-date allocation strategies and guidelines in order to maximise public health gain from the limited organs that are available.

Figure 1. The 10 year cumulative risk of graft failure or death following a kidney transplant from a deceased donor aged 55 to 70 year, by recipient age.



### ERA-EDTA Registry activities during the 53<sup>rd</sup> ERA-EDTA Congress in Vienna, Austria

#### CME 20: Cross-talk in Renal Epidemiology Saturday May 21, 15:30 – 17:30 h, Hall M

- Transitional research in nephrology - Public Health  
*Simon Fraser, United Kingdom*
- Chances and challenges of using routine data collections for renal health care research.  
*Gert Mayer, Austria*
- Prediction models  
*Benedicte Stengel, France*
- The credibility of subgroup analysis  
*Georg Heinze, Austria*
- Choosing the correct competing risk method - not always straightforward  
*Vianda Stel, The Netherlands*
- STROBE and the quality of reporting observational studies in nephrology  
*Fergus Caskey, United Kingdom*

#### Symposium 3 ERA-EDTA Registry Symposium

Sunday May 22, 8:00 – 9.30 a.m., Hall E

- Lifetime risk of Renal Replacement Therapy in Europe  
*Jan Van Den Brand, The Netherlands*
- Transplanting kidneys from older deceased donors: a comparison of outcomes in young and old recipients  
*Maria Pippias, The Netherlands*

- Vascular access in children on hemodialysis  
*Michael Böhm, Austria*
- The effect of age on the prevalence of protein energy wasting among elderly Stage 4 CKD patients  
*Marie Evans, Sweden*
- Beta-blockers and outcomes in diabetic dialysis patients: data from EURO DOPPS  
*Christiane Drechsler, Germany*

#### Posters

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

#### ERA-EDTA Registry booth

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

