Papers published per year

After an excellent starting phase led by Jane Tizard and Enrico Verrina, the ESPN/ERA-EDTA Registry managed to substantially increase its publications and the corresponding impact factors during the (vice) chairman period of Franz Schaefer and Jaap Groothoff. Of course this would not have been possible without the efforts of all other Registry committee members and all the countries contributing data. The figure below summarizes the number of publications and impact factor per year. The dashed areas represent the submitted manuscripts.

Highlights of 2015

With this newsletter we would like to update you on the latest activities of the ESPN/ERA-EDTA Registry. With the help of all those contributing data, we were able to publish 7 papers in 2015 (see list of publications for further details). Several other papers have been submitted, and various other projects are ongoing.

Two guest researchers visited the Registry during 2015. Dinara Galiyeva, a paediatrician from Kazakhstan/PhD student at the University of Edinburgh received an ERA-EDTA fellowship to visit the Registry to work on a project about the cardiovascular risk profile. During the summer, guest researcher and paediatric nephrologist, Michael Böhm from Austria, performed analyses for a project on vascular access. Next year various other researchers will visit the ESPN/ERA-EDTA Registry to perform an internship.

During the ESPN congress in Brussels an ESPN/ERA-EDTA Registry symposium was held in which several of the ongoing research projects were presented (more information below).

Furthermore, elections for the vice-chair position of the Registry Committee, as well as for a registry representative were held. Jaap Groothoff has replaced Franz Schaefer as chairman and Jerome Harambat was elected as vice-chairman. Constantinos Stefanidis and Anna Bjerre will be registry representatives on the Registry committee for the next three years.

We would especially like to thank Franz Schaefer for his great dedication to the Registry over the past years.

We would also like to thank all the contributors of the Registry and look forward to collaborating with you in 2016!

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Internships
The ESPN/ERA-EDTA Registry always welcomes individuals interested in performing an internship on the Registry. There are multiple projects available, but individuals with original ideas are very welcome. Please contact the registry staff if you would like to obtain more information about projects and funding for this.

ESPN 48th Annual Scientific Meeting
In September, a successful edition of the ESPN congress was held in Brussels. During the Registry Symposium there were presentations from Julien Hogan, who presented data on gender differences on the transplant waiting list, Marjolein Bonthuis, who presented data on longitudinal growth after transplantation, Lidwien Tjaden, who presented data on ethnic disparities in RRT outcomes, and Nick Chesnaye, who presented data on patient survival on RRT in Europe.

Furthermore, Fatos Yalcinkaya presented data on outcomes of children with prune belly syndrome on RRT.

Vascular access
By Michael Böhm

I am a paediatric nephrologist at the Department for Pediatric Nephrology and Gastroenterology, Medical University Vienna. My main scientific focus is on experimental PD and epidemiology of chronic renal failure and RRT. I had the opportunity of a short research stay for 2 months in order to analyze outcome data about vascular access in children on HD as first RRT modality collected by the ESPN/ERA-EDTA Registry. We identified 555 patients (median age: 13.8 years; IQR: 9.6-16.7; female: n=241) who started HD either on arteriovenous fistula (AVF: n= 241; 43.4 %) or central venous catheter (CVC: n= 314; 56.6 %) as first RRT from 2000 to 2013. Patients with CVC were significantly younger, showed lower Hb levels, and were more likely registered with an "unknown diagnosis". One third of CVC patients switched during HD therapy to an AVF, the overall risk for switching the access in the CVC group was fourfold higher. Patients with CVC as first access showed a higher likelihood for living related donor transplantation as compared to patients who started HD with AVF.

Results will be presented at the ERA/EDTA meeting in Vienna in May 2016.

Cardiovascular risk profile
By Dinara Galiyeva

I am a PhD student from the University of Edinburgh. My project is mainly focused on cardiovascular risk factors and their association with mortality in children with chronic kidney disease. As part of my PhD project I performed analyses on cardiovascular risk profile in children receiving RRT using data collected by the ESPN/ERA-EDTA Registry. To support this work I received a short-term ERA-EDTA fellowship to visit the Registry for three months from March until May 2015. Obtained results were presented in the annual meeting of the Scottish Renal Association in Dundee, Scotland in October 2015 and will be described in my PhD thesis. During the work at the Registry I gained an excellent experience, improved my epidemiological skills and obtained more knowledge on methods of data analysis. My clinical background as a paediatrician along with the epidemiological skills that I obtained performing research at the University of Edinburgh helped me to analyze, interpret and critically appraise the results that we achieved during this project. The next step is going to expand on this analysis by extending the follow up time.