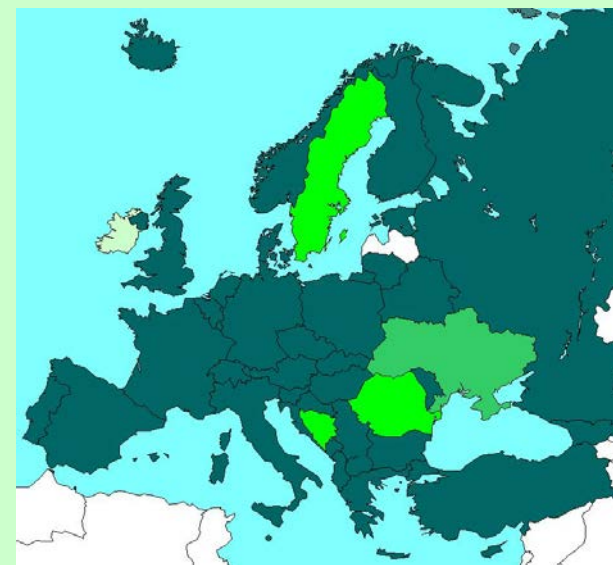





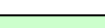
ESPN/ERA-EDTA Registry Scientific Committee

Jaap Groothoff, the Netherlands, chairman*
Jerome Harambat, France, vice-chairman*
Elena Levchenko, Belgium
Dieter Haffner, Germany
Kitty Jager, the Netherlands
Constantinos Stefanidis, Greece
Anna Bjerre, Norway
Ziad Massy, France
*ESPN representatives on the ERA-EDTA Registry Committee

ESPN/ERA-EDTA Registry Staff

Marjolein Bonthuis (Registry coordinator)
Nick Chesnaye (PhD candidate)
Karlijn van Stralen (Advisor)



-  Provided extended data to the ESPN/ERA-EDTA Registry
-  Provided limited data to the ESPN/ERA-EDTA Registry
-  Provided data via the ERA-EDTA Registry
-  Intend to contribute data in the near future

ESPN/ERA-EDTA Registry

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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.

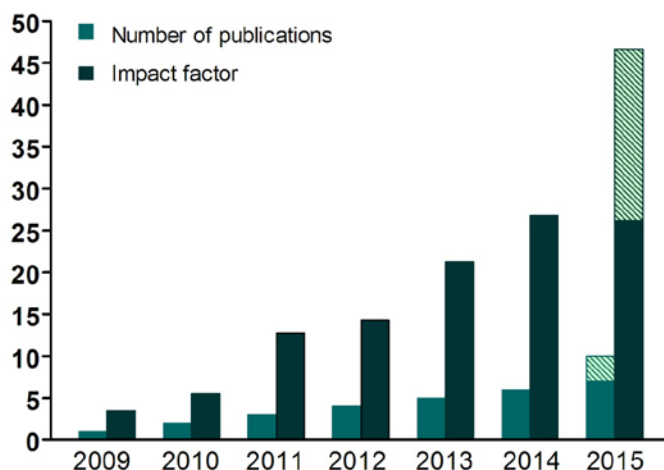
During the ESPN congress in Brussels an ESPN/ERA-EDTA Registry symposium was held in which several of the ongoing research projects were presented (more information below).

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!

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.



Publications 2015

Bonthuis M, Busutti M, van Stralen KJ, Jager KJ, Baiko S, Bakkaloglu S, Battelino N, Gaydarova M, Gianoglio B, Parvex P, Gomes C, Heaf JG, Podracka L, Kuzmanovska D, Molchanova MS, Pankratenko TE, Papachristou F, Reusz G, Sanahuja MJ, Shroff R, Groothoff JW, Schaefer F, Verrina E.

Mineral Metabolism in European Children Living with a Renal Transplant: A European Society for Paediatric Nephrology/European Renal Association-European Dialysis and Transplant Association Registry Study
Clin J Am Soc Nephrol. 2015 May 7; 10(5): 767-75

Chesnaye NC, Schaefer F, Groothoff JW, Caskey FJ, Heaf JG, Kushnirenko S, Lewis M, Mauel R, Maurer E, Merenmies J, Shtiza D, Topaloglu R, Zaicova N, Zampetoglou A, Jager KJ, van Stralen KJ

Disparities in treatment rates of paediatric end-stage renal disease across Europe: insights from the ESPN/ERA-EDTA registry

Nephrol Dial Transplant. 2015 AUG; 30(8): 1377-85

van Huis M, Bonthuis M, Sahpazova E, Mencarelli F, Spasojevic B, Reusz G, Caldas-Afonso A, Bjerre A, Baiko S, Vondrak K, Molchanova EA, Kolvek G, Zaikova N, Bohm M, Ariceta G, Jager KJ, Schaefer F, van Stralen KJ, Groothoff JW.

Considerable variations in growth hormone policy and prescription in paediatric end-stage renal disease across European countries-a report from the ESPN/ERA-EDTA registry.

Nephrol Dial Transplant. 2015 Apr 28. pii: gfv105.

[Epub ahead of print]

Lofaro D, Jager KJ, Abu-Hanna A, Groothoff JW, Arikoski P, Hoecker B, Roussey-Kesler G, Spasojević B, Verrina E, Schaefer F, van Stralen KJ; ESPN/ERA-EDTA Registry.

Identification of subgroups by risk of graft failure after paediatric renal transplantation: application of survival tree models on the ESPN/ERA-EDTA Registry.

Nephrol Dial Transplant. 2015 Aug 27. pii: gfv313.

[Epub ahead of print]

Krischock LA, van Stralen KJ, Verrina E, Tizard EJ, Bonthuis M, Reusz G, Hussain FK, Jankauskiene A, Novljan G, Spasojević-Dimitrijeva B, Podracka L, Zaller V, Jager KJ, Schaefer F; ESPN/ERA-EDTA Registry.

Anemia in children following renal transplantation-results from the ESPN/ERA-EDTA Registry

Pediatr Nephrol. 2015 Sep 18. [Epub ahead of print]

Harambat J, Bonthuis M, Groothoff JW, Schaefer F, Tizard EJ, Verrina E, van Stralen KJ, Jager KJ

Lessons learned from the ESPN/ERA-EDTA Registry

Pediatr Nephrol. 2015 Oct 24. [Epub ahead of print]

Tjaden LA, Noordzij M, van Stralen KJ, Kuehni CE, Raes A, Cornelissen EA, O'Brien C, Papachristou F, Schaefer F, Groothoff JW, Jager KJ

Racial disparities in access to and outcomes of kidney transplantation in children, adolescents, and young adults: Results from the ESPN/ERA-EDTA (European Society of Pediatric Nephrology/European Renal Association-European Dialysis and Transplant Association) Registry

Am J Kidney Dis. 2015 Nov 7. [Epub ahead of print]

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.

