



## ESPN/ERA-EDTA Registry Scientific Committee

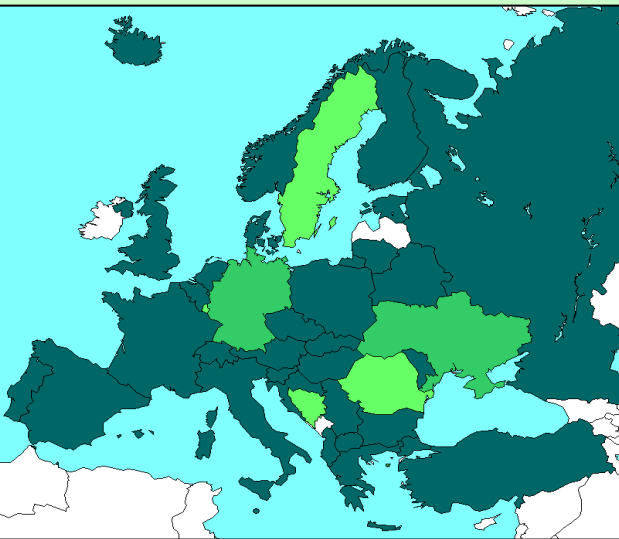
Franz Schaefer, Germany, chairman\*  
Jaap Groothoff, the Netherlands, vice-chairman\*

Jerome Harambat, France  
Constantinos Stefanidis, Greece  
Rosanna Coppo, Italy  
Dieter Haffner, Germany  
Christoph Wanner, Germany  
Kitty Jager, the Netherlands

\* ESPN representatives on the ERA-EDTA Registry Committee

## ESPN/ERA-EDTA Registry Staff

Karlijn van Stralen (study coordinator)  
Marjolein Bonthuis  
Nick Chesnaye  
Sean Senecal



## Highlights of 2013

With this newsletter we would like to update you on the latest activities of the ESPN/ERA-EDTA registry. Because of the great efforts of all those contributing, we were able to publish 8 papers in 2013 (see list of publications for further details) and various other projects are ongoing.

Many different researchers visited the registry. In the beginning of this year Marco Busutti, a medical student from Italy, worked on a project on mineral metabolism during a three month period. Maike van Huis, a PhD student from the Netherlands studied differences in Europe with respect to growth hormone policies. Very recently, Enrico Vidal, a paediatric nephrologist from Italy, visited the registry to perform a study on infant dialysis. At the moment Tuula Hölttä from Finland is working on a project on Finnish type nephropathy, for which she outlines the details below.

In March, a fruitful workshop was held in Genoa to share the experiences of the Registry regarding the epidemiology, management and treatment of paediatric patients on renal replacement therapy, with other registries and working groups which are currently active in the field of renal diseases.

Furthermore, the registry staff was extended with two people. Nick Chesnaye started as a PhD student focusing on the disparities in paediatric renal care in Europe. Sean Senecal started as data manager working on the improvement of the importer as well as data quality. They will introduce themselves below.

**We thank all the contributors of the registry and look forward to collaborating more in 2014!**

## Introducing Nick Chesnaye



As of March 2013, I started my PhD at the ESPN/ERA-EDTA registry in Amsterdam, which will focus on the disparities in paediatric renal care in Europe. The incidence of RRT in children varies greatly amongst European countries. The objective of my first project is to describe and explain this variation.



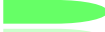
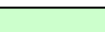
To achieve this, we reviewed the literature and consulted paediatric nephrologists within the ESPN/ERA-EDTA network to identify potential country-level factors that may explain these differences. This resulted in the construction of a conceptual framework describing country-level factors related to –amongst others– macroeconomics, health care system characteristics, and access to care, and their potential influence on RRT incidence. A survey was developed to collect this information from countries, and other country factors were collected from the World Bank database. Preliminary analyses show that macroeconomic indicators have a strong positive effect on the incidence, with wealthier countries spending more on health care having a higher incidence compared to less wealthier countries. Pending the survey results, we hope to soon expand on these analyses. The results of this ecological study will hopefully contribute to identifying barriers for paediatric RRT, and in doing so reduce inequalities in the provision of paediatric renal services throughout Europe.

I look forward to working together with you in the upcoming years!

## ESPN/ERA-EDTA Registry

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Email: [K.J.vanStralen@amc.uva.nl](mailto:K.J.vanStralen@amc.uva.nl)

-  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

### Publications 2013

Harambat J, van Stralen KJ, Verrina E, Groothoff JW, Schaefer F, Jager KJ  
**Likelihood of children with end-stage kidney disease in Europe to live with a functioning kidney transplant is mainly explained by nonmedical factors.** *Pediatr Nephrol* 2013; Nov 15 [Epub ahead of print]

Harambat J, Bonthuis M, van Stralen KJ, Ariceta G, Battelino N, Bjerre A, Jahnukainen T, Leroy V, Reusz G, Sandes AR, Sinha MD, Groothoff JW, Combe C, Jager KJ, Verrina E, Schaefer F.  
**Adult height in patients with advanced CKD requiring renal replacement therapy during childhood.** *cJASN* 2013; Nov 7 [Epub ahead of print]

Bonthuis M, van Stralen KJ, Jager KJ, Baikou S, Jahnukainen T, Laube GF, Podracka L, Seeman T, Tyerman K, Ulinkski T, Groothoff JW, Schaefer F, Verrina E  
**Dyslipidaemia in children on renal replacement therapy.** *NDT* 2013; Oct 29 [Epub ahead of print]

Bonthuis M, van Stralen KJ, Verrina E, Groothoff JW, Alonso Melgar A, Edefonti A, Fischbach M, Mendes P, Molchanova EA, Paripović D, Peco-Antic A, Printza N, Rees L, Rubik J, Stefanidis CJ, Sinha MD, Zagodzón I, Jager KJ, Schaefer F

**Underweight, overweight, and obesity in paediatric dialysis and renal transplant patients.** *NDT* 2013; 28 Suppl 4: iv195-iv204

van Stralen KJ, Verrina E, Belingeri M, Dudley J, Dusek J, Grenda R, Macher MA, Puretic Z, Rubik J, Rudaitis S, Rudin C, Schaefer F, Jager KJ  
**Impact of graft loss among kidney diseases with a high risk of recurrence in the paediatric population.** *NDT* 2013; 28: 1031-8.

Bonthuis M, Jager KJ, Abu-Hanna A, Verrina E, Schaefer F, van Stralen KJ.  
**Application of Body Mass Index according to height-age in short and tall children.** *PLoS One*; e72068

Harambat J, van Stralen KJ, Schaefer F, Grenda R, Jankauskiene A, Kostic M, Macher MA, Maxwell H, Puretic Z, Raes A, Rubik J, Sørensen SS, Toots U, Topaloglu R, Tönshoff B, Verrina E, Jager KJ.  
**Disparities in policies, practices and rates of pediatric kidney transplantation in Europe.** *AJT* 2013; 13:2066-74

Wühl E, van Stralen KJ, Verrina E, Bjerre A, Wanner C, Heaf JG, Zurriaga O, Hoitsma A, Niaudet P, Palsson R, Ravani P, Jager KJ, Schaefer F.  
**Timing and outcome of renal replacement therapy in patients with congenital malformations of the kidney and the urinary tract.** *CJASN*. 2013; 8:67-74

### 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.



### Registry committee meeting Genoa March 2013

From left to right: Marjolein Bonthuis, Franz Schaefer, Constantinos Stefanidis, Rosanna Coppo, Kitty Jager, Jaap Groothoff, Jerome Harambat (missing Karlijn van Stralen)

### Introducing Sean Senecal



My name is Sean Senecal and since February of this year I am working as data manager for the ESPN/ERA-EDTA registry. The first months of this year I checked all incoming and existing data on irregularities. After that, I worked on importing all data into the database and on creating an informative benchmark for the participating countries.

The last months of this year I have been looking at ways to improve the import function of the ESPN/ERA-EDTA web application, in order to be able to import the data more efficiently in the nearby future.

### Project of Tuula Hölttä

*Congenital nephrotic syndrome of the Finnish type*

I am a paediatric nephrologist from Children's Hospital, University of Helsinki, Finland and performed my PhD in peritoneal dialysis in children in Finland in 2000. I came as a visiting researcher to the AMC in Amsterdam for a period of 3 weeks in December 2013, to analyze the ESPN/ERA-EDTA registry data on Finnish type CNS.

Over 200 patients were identified from 10 participating countries. The patients were followed from start of the RRT until death or end of the year 2011. Almost one third of the patients were from Finland.

The Finnish patients were significantly younger at the start of RRT (8 months) as compared to patients from other countries (2 years). Furthermore, the treatment strategy seems to very different with highly frequent bilateral nephrectomies in Finland. We are currently comparing the effects of these differences on patient and graft survival between patients from Finland and other countries. Interesting results will be published 2014.

