



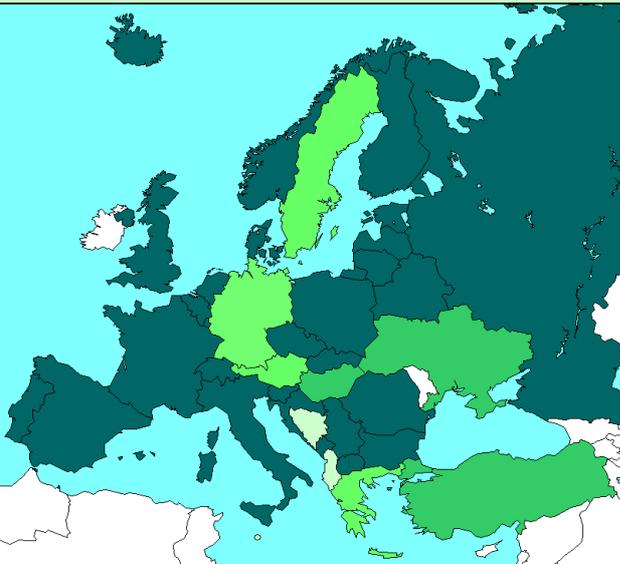
## ESPN/ERA-EDTA Registry Scientific Committee

Franz Schaefer, Germany, chairman\*  
Jaap Groothoff, Netherlands, vice-chairman\*  
Jerome Harambat, France  
Constantinos Stefanidis, Greece  
Dieter Haffner, Germany  
Rosanna Coppo, Italy  
Christoph Wanner, Germany  
Kitty Jager, Netherlands

\* ESPN representatives on the ERA-EDTA  
Registry Committee

## ESPN/ERA-EDTA Registry Staff

Karlijn van Stralen (study coordinator)  
Marjolein Bonthuis  
Mark Titulaer



- 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

Department of Medical Informatics  
Academic Medical Center  
Room J1B-125  
1105 AZ Amsterdam  
The Netherlands

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

## Highlights of 2012

We would like to thank everybody for their great participation and enthusiasm in the Registry, which all contributed to its success in 2012.

Because of the renewal of the generous grant by the ERA-EDTA until 2016, as well as a grant from the EAHC, the registry staff can now be extended with an additional data manager and a new PhD student (see below).

Furthermore, during the ESPN congress Jaap Groothoff was elected as the vice-chairmen of the Registry. Because he was already Registry representative, there were new elections for his position. Constantinos J. Stefanidis was elected by the Registries to be the new representative.

Five papers have been accepted and published (see list for publications) and another four are currently under review at various journals. Fourteen countries successfully used the online data collection system to enter their patient data. We also extended the annual report with some benchmarking variables like blood pressure and height.

Again, many visiting researchers performed studies within the registry. Huib de Jong, a Dutch paediatric nephrologist, visited the AMC to work on a project about graft loss in very young patients. Danilo Lofaro (Italy) visited the registry for six months and worked on a project identifying subgroups at high risk for graft failure (more information can be found below). In January 2013, Marco Busutti, a medical student from Italy, will visit the registry office to perform an internship about calcium phosphate metabolism.

Next year many new research projects will be started in which we hope to collaborate with you in order to make 2013 such a successful year again.

**Thank you again, enjoy the holidays and a happy new year!**

## 45th ESPN Annual Scientific Meeting in Krakow

For the first time there was a special session devoted to the ESPN/ERA-EDTA registry during the ESPN conference in Krakow. During this session an overview of all research projects performed within the registry was given by Karlijn van Stralen. Enrico Verrina presented data from the Annual Report.

Franz Schaefer presented a project on CAKUT as cause of RRT in children and adults, and Jérôme Harambat gave an overview of paediatric kidney transplantation activity and practices across Europe. As registry staff members, we look back at a very successful session, which will hopefully continue to exist during future meetings.



Further, Huib de Jong, Danilo Lofaro, Jérôme Harambat, and Marjolein Bonthuis gave oral presentations about their research projects during the conference.

## Publications 2012

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.

*Clin J Am Soc Nephrol.* 2012; Oct 18 [Epub ahead of print].

Van Stralen KJ, Krischock L, Schaefer F, Verrina E, Groothoff JW, Evans J, Heaf J, Ivanov D, Kostic M, Maringhini S, Podracká L, Printza N, Pundziene B, Reusz GS, Vondrak K, Jager KJ, Tizard EJ.

### Prevalence and predictors of the sub-target Hb level in children on dialysis.

*NDT.* 2012 Oct;27(10):3950-3957.

Bonthuis M, van Stralen KJ, Verrina E, Edefonti A, Molchanova EA, Hokken-Koelega ACS, Schaefer F, Jager KJ.

### Use of National and International growth charts for studying height in European children: development of up-to-date European height-for-age charts

*PLoS One* 2012;7(8):e42506.

Harambat J, van Stralen KJ, Espinose L, Groothoff JW, Hulton SA, Cerkauskiene R, Schaefer F, Verrina E, Jager KJ, Cochat P.

### Characteristics and outcomes of children with primary oxalosis requiring renal replacement therapy.

*Clin J Am Soc Nephrol.* 2012;7:458-65.

Harambat J, van Stralen KJ, Kim JJ, Tizard EJ.

### Epidemiology of chronic kidney disease in children.

*Pediatr Nephrol.* 2012;27:363-73

## Funding

The ESPN/ERA-EDTA registry is generously funded by the ESPN and the ERA-EDTA. Furthermore, the research projects of the visiting researchers have been funded by short-term fellowship grants from the ERA-EDTA. If you would like to perform an internship on the registry, there are also small funds available through the ESPN.

Please contact our registry staff if you would like to obtain more information about performing an internship on the registry.

## ERA-EDTA Grant

The ERA-EDTA kindly renewed the grant provided to the ESPN/ERA-EDTA registry through March 2016. We are highly indebted to this generous offer from the ERA-EDTA. Additional focus points for the upcoming years include education and the transition between childhood and adulthood, and the presence of "paediatric diseases" in adult age. The collaborative project on the age of start of Renal replacement therapy in patients with congenital anomalies of the kidney and urinary tract (CAKUT) by Elke Wühl is a nice example of this, in which we show that CAKUT is not only a paediatric disease. Similar projects on Henoch Schonlein and IgA nephropathy are currently ongoing. We hope that by performing such projects we will improve the understanding of specific paediatric disorders in adulthood.

## EAHC Grant

The Executive Agency for Health and Consumers (EAHC), an institution of the European Commission, has kindly provided a grant to the ESPN/ERA-EDTA Registry. The main purpose of this grant includes studying health inequalities. In our emerging Europe-wide registry we observe major differences between countries with respect to the incidence and prevalence of paediatric renal replacement therapy. We would like to study the reasons for these differences between countries.

- Amongst others, we will study differences concerning the causes of renal failure between countries, as well as differences in the strategies and timing of renal replacement therapy.
- In a second step, we would like to study differences with respect to the prescription of medications. Each country adheres to different policies, e.g. regarding growth hormone treatment, dosing of ESAs etc. We plan to map these variations of practice patterns.
- Subsequently we would like to compare policies in relation to outcomes across European countries.

We hope that such analyses will optimize health care in the field of paediatric nephrology in Europe and are grateful to the EAHC for providing this grant.

## Project of Danilo Lofaro

### Identification of subgroups at high risk of graft failure after paediatric renal transplantation

Identification of patients potentially at higher risk of graft loss before kidney transplantation could help both physicians and families in taking important decisions with respect to, amongst others, living versus deceased donation and timing of transplantation.

A new methodology called "survival tree analysis" was used to analyze the ESPN/ERA-EDTA registry data on paediatric kidney transplantation in order to identify specific subgroups of patients with substantially different patterns of 5-year graft survival and to evaluate the interactions among different pre-transplant factors.

The best 5-year graft survival (90.4%) was found among patients receiving transplantation pre-emptively or after short-term dialysis (<45 days), whereas survival was poorest (51.7%) in adolescents transplanted after long-term dialysis (>2.2 years). Six more subgroups were identified by the interactions among time on dialysis, recipient age, gender, type of donor, and cause of renal failure.

