

ESPN/ERA-EDTA Registry

Registry of the European Society for Paediatric Nephrology



ESPN <http://espn.cardiff.ac.uk>

ESPN/ERA-EDTA Registry <http://www.espn-reg.org>

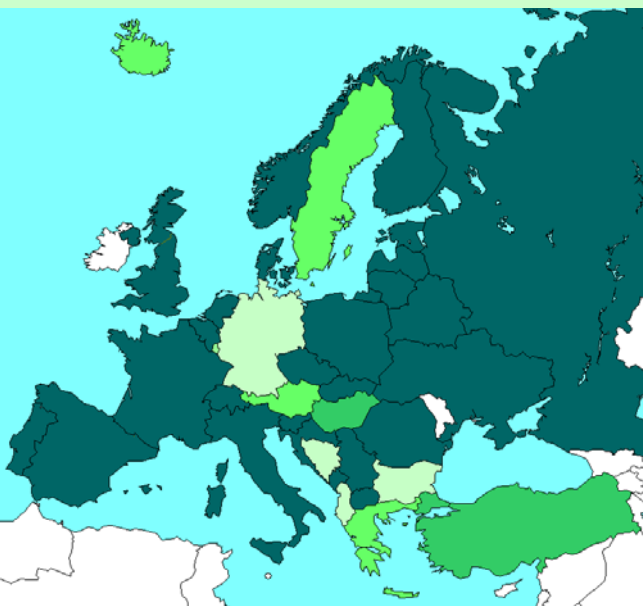
ESPN/ERA-EDTA Registry Scientific Committee

Enrico Verrina, Italy, chairman*
Franz Schaefer, Germany, vice-chairman*
Pierre Cochat, France
Rosanna Coppo, Italy
Dieter Haffner, Germany
Jaap Groothoff, the Netherlands
Malcolm Lewis, United Kingdom
Kitty Jager, the Netherlands

* ESPN representatives on the ERA-EDTA
Registry Committee

ESPN/ERA-EDTA Registry Staff

Karlijn van Stralen (study coordinator)
Marjolein Bonthuis
Jerome Harambat
Mark Titulaer



- Dark green: Provided extended data to the ESPN registry
- Medium green: Provided limited data to the ESPN registry
- Light green: Provided data via the ERA-EDTA registry
- Yellow: Intend to contribute data in the near future

ESPN/ERA-EDTA Registry

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Highlights of 2010

In this first Newsletter of the Registry we would like to thank you for the great participation in the Registry. Last year was a very good year for the ESPN/ERA-EDTA Registry. Even more countries contributed data to the Registry. Because of the large database and all the variables, the size of the annual report was doubled compared to last year. Furthermore, many interesting studies have been performed or are currently being carried out for which we also like to thank the experts from different countries for their great input.

In 2010, 3 papers were published and another 2 submitted. During the IPNA conference in New York 3 posters were presented: one on eGFR at the start of RRT, one on anemia and one on hypertension. The paper on hypertension is being revised for a journal.

Besides this, also the staff was extended. Therefore, in this newsletter we will introduce some of the new staff members.

Next year will be an exciting year as well, with many more projects to be performed and papers to be written. We would like to thank you again and we look forward to many collaborative research projects and hope to have an equally great data collection next year.

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



From left to right: Karlijn van Stralen, Mark Titulaer, Marjolein Bonthuis, and Kitty Jager (missing Jerome Harambat)

New Staff

Marjolein Bonthuis: a PhD student. The focus of her project is on nutrition related factors in pediatric ESRD patients.

Jerome Harambat: a pediatric nephrologist from France, who now works at the Registry on a one year project on pediatric renal transplantation in Europe to obtain his PhD-degree. His work is funded by a grant from the QUEST project.

Mark Titulaer: data manager. He is currently developing an internet-based data collection tool to facilitate data-collection for the registry. A pilot of data collection will be held in the beginning of next year.

Publications 2010

- van Stralen KJ, Tizard EJ, Verrina E, Schaefer F, Jager KJ; on behalf of the European Society for Paediatric Nephrology/European Renal Association-European Dialysis and Transplant Association (ESPN/ERA-EDTA) registry study group.
Demographics of paediatric renal replacement therapy in Europe: 2007 annual report of the ESPN/ERA-EDTA registry.
Pediatr Nephrol. 2010 Jul;25(7):1379-82.
- van Stralen KJ, Tizard EJ, Jager KJ, Schaefer F, Vondrak K, Groothoff JW, Podracká L, Holmberg C, Jankauskiené A, Lewis MA, van Damme-Lombaerts R, Mota C, Niaudet P, Novljan G, Peco-Antic A, Sahpazova E, Toots U, Verrina E
Determinants of eGFR at start of renal replacement therapy in paediatric patients.
Nephrol Dial Transplant. 2010 Oct;25(10):3325-32.
- van Stralen KJ, Jager KJ, Verrina E, Schaefer FS, Emma F.
Suggested revision of the National High Blood Pressure Education Program blood pressure standardization for severely growth retarded children.
Pediatric Nephrol. Ahead of print.

Posters

- Krishock LA, van Stralen KJ, Jager KJ, Verrina E, Groothoff JW, Schaefer F, Tizard JE.
The Prevalence and Predictors of Anaemia in European Children with Established Renal Failure.
- van Stralen KJ, Tizard JE, Jager KJ, Schaefer F, Verrina E.
Determinants of eGFR at Start of Renal Replacement Therapy
- Kramer AM, van Stralen KJ, Jager KJ, Schaefer F, Verrina E, Groothoff JW.
Hypertension in Pediatric Renal Replacement Therapy Patients in Europe

Funding:

The ESPN/ERA-EDTA registry is being funded by ESPN, ERA-EDTA, and through the NephroQUEST project. The NephroQUEST project has received funding from the European Union in the framework of the public Health Programme (project number 2006114).

Research projects of new staff

Jerome Harambat and Marjolein Bonthuis



Jerome Harambat

After training in Pediatrics and Epidemiology in Bordeaux and Lyon, France, I started a PhD on the Registry last November. My focus will be on renal transplantation strategies and outcomes. I will first perform a survey on differences in policies and practices of transplantation across Europe. Indeed, such differences may impact the equity of renal transplantation as well the patient and graft survival. We are planning to send this survey to all pediatric nephrologists in Europe in January, so we sincerely hope that you will all collaborate in this

project. Then, I will study some clinical outcomes like growth post transplantation.

Marjolein Bonthuis

Last April I started as a PhD student on the Registry after obtaining my MSc degree in Nutrition and Health. I will perform studies on nutrition related factors. My current focus is on growth and nutritional status. Growth charts are mainly used to monitor whether growth is healthy. In Europe, many different growth charts are currently used, but for studies within the Registry one chart might be necessary to make meaningful comparisons across the countries. For this, we made a small inventory and we really appreciate your help. At the moment I am working to find the most optimal growth chart to be used within future studies. After finishing this I will focus on clinical aspects related to the nutritional status.



CME Introductory Course on Epidemiology

In September 2011, the 44th Annual Scientific Meeting of the European Society for Paediatric Nephrology will take place in Dubrovnik, Croatia. The ERA-EDTA Registry and some of the staff members of the ESPN/ERA-EDTA registry will give a pre-congress course on epidemiology on September 13-14, 2011. The aim of this epidemiology course is to teach nephrologists and nephrology researchers basic epidemiology principles and to have them practice their new skills in hands on sessions (exercises, discussions and SPSS). **This time, the course primarily aims at pediatric nephrologists.** Two travel grants are kindly provided by the ERA-EDTA. If you are interested in participating in this course more information can be found on <http://www.ndt-educational.org/Dubrovnik2011.htm>.