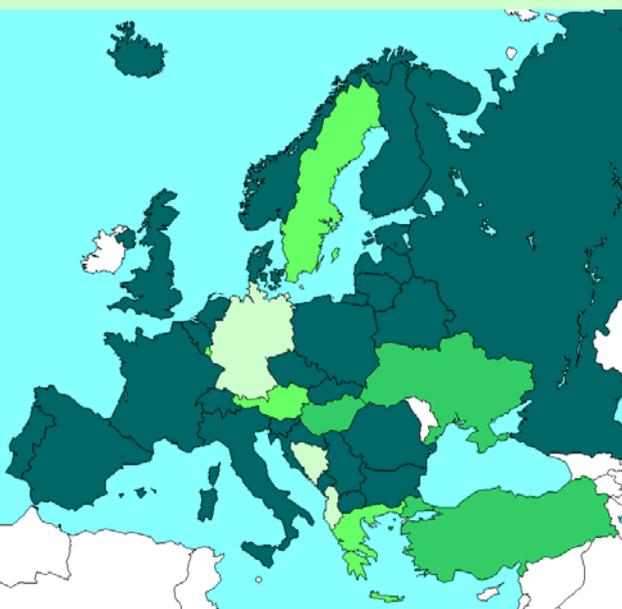


ESPN/ERA-EDTA Registry Scientific Committee

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

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Highlights of 2011

First of all, we would like to thank you for your great participation in the Registry in 2011, which has been a highly successful year. Besides many papers being published and submitted, many visiting researchers performed studies within the registry.

Jerome Harambat (France) visited the Registry for one year. His first project resulted in a review on epidemiology in CKD which has been published in Pediatric Nephrology and a paper on oxalosis which has been accepted by the clinical JASN. One other paper on transplant policies is under review and details of his project can be found below. Finally a final paper on final height is under way.

Elke Wühl (Germany) visited the registry for one month during the summer for a project on congenital anomalies of the kidney and the urinary tract. They both received a fellowship grant from the ERA-EDTA.

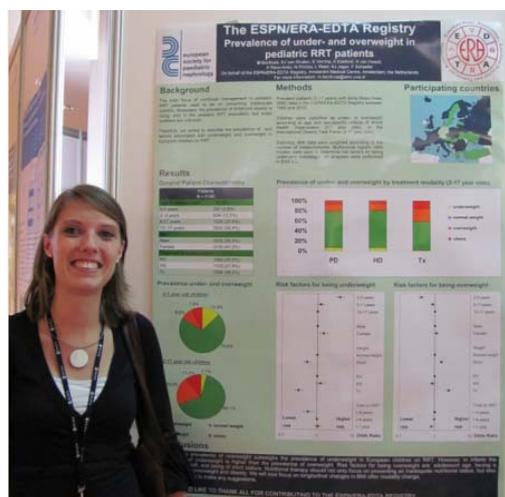
We are also very happy to inform you that Danilo Lofaro from Italy received a generous grant from the ERA-EDTA to perform a 6 months project on risk factors for graft failure starting from February 2012.

This year we started the online data collection. Currently, eight countries provided data via this tool and we hope in the future many more countries will be using it. More information on this tool can be found below

In 2011, so far 5 papers are accepted and published (see list of publications), and another 3 have been submitted for publication.

As all these projects were not possible without the work of all the experts involved in the registry, and all those contributed with data, we would like to thank everybody for the great participation and enthusiasm. We hope to collaborate with you in the future to make 2012 such a successful year as well.

44th ESPN Annual Scientific Meeting in Dubrovnik



During the ESPN congress in Dubrovnik the Registry was well represented. Four research projects were presented orally: one on transplantation policies in Europe, one on anemia in children on dialysis, one on neonatal onset of RRT, and one on the comparison of growth charts for height. Furthermore, also four posters were presented.

Poster by Marjolein Bonthuis entitled: 'Prevalence of underweight and overweight In European pediatric patients on RRT'

Publications 2011

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. In press

Van Stralen KJ, Emma F, Jager KJ, Verrina E, Schaefer F, Laube GF, Lewis MA, Levtchenko EN.

Improvement in the renal prognosis in nephropathic cystinosis.

Clin J Am Soc Nephrol. 2011 Oct 6(10): 2485-91.

Kramer AM, van Stralen KJ, Jager KJ, Schaefer F, Verrina E, Seeman T, Lewis MA, Boehm M, Simonetti GD, Novljan G, Groothoff JW.

Demographics of blood pressure and hypertension in children on renal replacement therapy in Europe.

Kidney Int. 2011 Nov 80(10): 1092-8.

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

Epidemiology of chronic kidney disease in children.

Pediatr Nephrol. 2011 June 29 Epub Ahead of Print.

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.

Pediatr Nephrol. 2011 May 26(5):819-820.

Funding

The ESPN/ERA-EDTA registry is generously funded by the ESPN and the ERA-EDTA. Furthermore, the research projects by the visiting researchers have been funded by the QUEST project and 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 by the ESPN.

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

Introducing registry staff



Mark Titulaer

I am a biochemist / bioinformatician with experience in proteomics and biomarker research on large mass spectrometry datasets. After a post-doctoral position at the Erasmus Medical Centre in Rotterdam to find biomarkers for different brain tumors, I started almost two years ago, with the development of a secure web application for ESPN/ERA-EDTA registry for on-line import of pediatric nephrology data.

Internet-based data collection

The on-line data entry system allows for a safe data entry. Countries who want to contribute data via this system can obtain a login-name and password via the registry. They only have access to their own patients. This access allows them to enter patient data such as baseline data, events and follow-up data in a secure way. Furthermore, these entries are directly checked for accuracy.

In the future we want to extend this programme with direct feedback to the data-contributor about how the patient is doing compared with his or her peers.

Gender:	Male	Treatment:	HD	11-10-2011	Last follow-up:	Transplantation 24-10-2011
Center:	testcenter2	Last event:	Change to HD	11-10-2011		
Patient Baseline Events: Changes of treatment modality, recovery of renal function and information at time of transplantation Follow-up dialysis Follow-up transplantation						
<input type="button" value="submit"/>		<input type="button" value="cancel"/>				
Date of Measurement (dd-mm-yyyy)				05-12-2011	<input type="button" value="select"/>	
Extended A (high priority data collection) - therapy at this moment						
Clinical characteristics						
Parathyroidectomy ?				<input checked="" type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown		
Systolic blood pressure - pre dialysis				<input type="text"/>		
Diastolic blood pressure - pre dialysis				<input type="text"/>		
Height (cm)				<input type="text"/>		
Weight (kg)				<input type="text"/>		

An excerpt of the Graphical User Interface of the web-based application

Project of Jerome Harambat

Policies and practices of paediatric kidney transplantation

Paediatric kidney allocation policies and transplantation practices may vary according to the country. These variations may lead to unequal access to kidney transplantation within Europe, and therefore to differences in morbidity and survival in children with ESRD.

In 2011, a survey was distributed among renal registry representatives in 38 European countries. There were considerable differences in practices and access to paediatric kidney transplantation across Europe, as 5.7 per million children population received a transplantation, but this ranged from 0 to 13.5 between countries. A median of 17% of transplants was performed preemptively while a median of 43% received a graft from a living donor. Access to kidney transplantation was associated with non-medical factors such as the Gross Domestic Product per capita, and medical factors including national deceased donation rate, paediatric priority category, and living donor paediatric transplant rate.