

ESPN/ERA-EDTA Registry

Registry of the European Society for Paediatric Nephrology and the European Renal Association and European Dialysis and Transplantation Association



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

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

by Karlijn van Stralen, Marjolein Bonthuis, Enrico Verrina, Franz Schaefer and Kitty Jager

An update on the Registry



Enrico Verrina and Franz Schaefer

As members of the ESPN/ERA-EDTA Registry committee we want to thank you again for the fantastic participation in and enthusiasm for the Registry. Currently 32 countries participate in the registry providing information regarding 10,000 patients who started RRT before the age of 20 between 1997 and 2010.

But there is more! In the past months

two clinical papers based on registry data, as well as a two educational papers, have been accepted for publications.

Secondly, this year two visiting researchers came to the AMC. Jerome Harambat from Bordeaux (France) started in November for a one-year internship. He received a grant from the QUEST project and is working on four projects within the Registry. He started working on oxalosis, his second project was on transplantation policies and his final project will be on growth after transplantation. Furthermore, he wrote an educational review on the epidemiology of CKD¹. In July, Elke Wühl from Heidelberg (Germany) worked on a project on congenital anomalies of the kidney and urinary tract in both the paediatric registry as

well as the adult ERA-EDTA registry. She received a grant from the ERA-EDTA to support this project.

Finally, this year the internet-based data collection tool was launched. This allows for direct entry into the registry. We hope that this tool helps to facilitate the data-collection.

If you are interested in performing a research project on the registry or would like to know more about the participating in the ESPN/ERA-EDTA registry, please speak to us during the ESPN conference or contact Karlijn: K.J.vanStralen@amc.uva.nl.

We would like to thank you again for your great collaboration and hope to work together in many research projects thereby improving paediatric nephrology care and research in Europe.

Data analyses and publications

The ESPN/ERA-EDTA Registry collects data on RRT on an annual basis via the national renal registries in Europe. So far, data have been included from four subsequent years.

In 2009, the median incidence was 6.3 per million age-related population (pmarp) and ranged from 0, as no patients started RRT in that year, to 14.7 pmarp. The prevalence also shows a wide range from 9.8 to 79.8 pmarp. Two-year survival was 93.9% after start of RRT. The most important causes of death were infection and related to cardiovascular events.

As said above two papers have been accepted and published in the previous months. First, Kidney International has accepted the paper on hypertension in

children on renal replacement therapy², and second the clinical JASN accepted our paper on the improvement of prognosis in cystinosis patients³. In addition, we wrote a paper on a problem with the generally used method for defining hypertension in severely growth retarded children⁴. Furthermore, at this moment three other papers on oxalosis, growth reference charts and anemia in dialysis patients are under review at different journals.

During the ESPN conference, you will see and hear more results of registry. There are four oral presentations and four poster presentations. Please see page 5 for the details. **Thank you all for making this possible.**

Publication list ESPN/ERA-EDTA registry 2010-2011

¹Harambat J, van Stralen KJ, Kim JJ, Tizard EJ. Epidemiology of chronic kidney disease in children. *Pediatr Nephrol*. 2011. Available online.

²Kramer 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. Available online.

³Van 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. Available online.

⁴van Stralen KJ, Jager KJ, Verrina E, Schaefer F, Emma F. Suggested revision of the National High Blood Pressure Education Program blood pressure standardization for use in severely growth retarded children. *Ped Neph*, 2011; 26: 819-20.

Table 1: Incident patients

Incident paediatric patients accepted for renal replacement therapy in 2009 and general population characteristics of countries contributing 2009 data to the ESPN/ERA-EDTA registry.

Country	Total		General Population Characteristics		
	RRT patients 0-14 years		Children 0-14 years	Total Population 0-99 years	Children 0-14 years percent
	N	pmarp	N	N	
Austria	14	11.1	1,261,588	8,355,260	15.1
Belarus	6	4.2	1,415,055	9,671,912	14.6
Belgium	13	7.1	1,823,555	10,796,492	16.9
Bulgaria	5	4.9	1,023,899	7,585,132	13.5
Croatia	6	8.9	676,034	4,411,210	15.3
Czech republic	6	4.0	1,487,189	10,487,181	14.2
Denmark	15	14.7	1,017,620	5,579,429	18.2
Estonia	0	0.0	201,569	1,340,130	15.0
Finland	5	5.6	889,743	5,338,869	16.7
France	63	5.3	11,917,781	64,369,147	18.5
Greece	14	8.6	1,618,578	11,282,758	14.3
Hungary	9	6.1	1,484,731	10,022,647	14.8
Iceland	0	0.0	66,539	318,498	20.9
Italy*	35	4.1	8,453,322	60,192,697	14.0
Lithuania	3	6.0	502,119	3,339,455	15.0
Montenegro	0	0.0	122,100	631,531	19.3
Norway	8	8.7	914,970	4,828,725	18.9
Poland	38	6.5	5,806,110	38,151,603	15.2
Portugal	15	9.3	1,619,803	10,632,482	15.2
Republic of Serbia	4	3.6	1,115,001	7,320,805	15.2
Romania	16	4.9	3,257,994	21,480,400	15.2
Russia	55	2.6	21,246,520	141,909,244	15.0
Slovakia	5	6.0	833,694	5,418,587	15.4
Slovenia	1	3.5	285,665	2,039,670	14.0
Spain	56	8.1	6,877,111	46,883,418	14.7
Sweden	15	9.7	1,545,922	9,298,518	16.6
Switzerland	5	4.3	1,180,221	7,785,806	15.2
the Netherlands	28	9.6	2,917,986	16,530,387	17.7
United Kingdom	99	9.2	10,795,800	61,791,800	17.5
Total	540	5.8	92,358,481	587,751,817	15.7

* (pre-emptive) transplantation patients are not included, therefore the numbers are an underestimation of true incidence and prevalence

Table 2: Treatment modality at start of RRT

Treatment modality at day 1, among patients < 15 years of age, starting RRT in 2009, missing for 5 patients

	N	percent	pmarp
HD at start	173	32.3	1.9
PD at start	254	47.4	2.8
Pre-emptive transplantation	108	20.2	1.3

Table 3: PRD distribution at start of RRT

Treatment modality at day 1, among patients < 15 years of age, starting RRT in 2009

	N	percent	pmarp
Glomerulonephritis	63	11.7	0.69
Congenital anomalies of the kidney and urinary tract	163	30.7	1.80
Cystic kidney disease	43	8.0	0.47
Hereditary Nephropathy	23	4.3	0.20
Ischemic renal failure	8	1.5	0.08
HUS	22	4.1	0.20
Metabolic Disorders	17	3.1	0.19
Vasculitis	6	1.1	0.07
Pyelonephritis	10	1.9	0.11
Miscellaneous	59	10.9	0.61
Unknown	123	22.8	1.34

Table 4: eGFR at start of RRT

Estimated GFR based on age, height and serum creatinine levels, calculated according to the old Schwartz formula, among incident patients, aged 15 starting on RRT in 2009.

	N	percent
eGFR<8 ml min ⁻¹ per 1.73 m ²	38	49.4
eGFR 8- 15 ml min ⁻¹ per 1.73 m ²	23	29.9
eGFR>15 ml min ⁻¹ per 1.73 m ²	16	20.8

Table 5: Prevalent Patients

Prevalent paediatric patients on renal replacement therapy on the 31st of December 2009. Prevalent counts and prevalence per million age related population, by age groups of those countries contributing 2009 data to the ESPN/ERA-EDTA Registry.

Country	Total		Age Groups		
	RRT patients 0-14 years		Infants 0-4 years	Children 5-9 years	Adolescents 10-14 years
	N	pmarp	pmarp	pmarp	pmarp
Austria	59	46.8	30.3	36.8	69.9
Belarus	29	20.5	14.4	8.9	37.5
Belgium	98	53.7	25.7	53.9	82.4
Bulgaria	11	10.7	0.0	11.9	21.7
Croatia	22	32.5	18.9	14.2	59.5
Czech republic	35	23.5	21.7	25.8	23.5
Denmark	49	48.2	27.2	35.9	79.5
Estonia	2	9.9	0.0	31.2	0.0
Finland	71	79.8	64.1	87.0	88.3
France	361	30.3	11.0	30.9	49.4
Greece	53	32.7	17.8	26.8	54.4
Hungary	44	29.6	10.2	29.1	48.6
Iceland	2	30.1	0.0	46.8	45.3
Italy*	264	31.2	19.4	32.6	41.9
Lithuania	19	37.8	24.8	12.9	70.0
Montenegro	4	32.8	76.3	0.0	23.5
Norway	41	44.8	16.6	56.9	60.3
Poland	219	37.7	19.8	40.5	51.9
Portugal	70	43.2	21.0	52.1	55.7
Republic of Serbia	40	35.9	19.9	10.6	75.4
Romania	46	14.1	3.7	8.4	29.7
Russia	231	10.9	3.8	9.0	21.0
Slovakia	21	25.2	7.2	15.3	50.7
Slovenia	10	35.0	19.9	44.1	42.2
Spain	279	40.6	21.3	42.5	60.5
Sweden	76	49.2	31.3	46.3	71.0
Switzerland	50	42.4	18.5	52.4	54.9
the Netherlands	144	49.3	26.9	45.7	74.3
United Kingdom	597	55.3	28.6	49.9	88.3
Total	2942	31.9	15.9	30.4	50.0

* (pre-emptive) transplantation patients are not included, therefore the numbers are an underestimation of true incidence and prevalence

Table 5: Prevalent Patients (continued)

Prevalent paediatric patients on renal replacement therapy on the 31st of December 2009. Prevalent counts and prevalence per million age related population, by gender and treatment modality of those countries contributing 2009 data to the ESPN/ERA-EDTA Registry

Country	Gender		Treatment Modality		
	Males	Females	HD	PD	Transplantation
	0-14 years pmarp	0-14 years pmarp	0-14 years pmarp	0-14 years pmarp	0-14 years pmarp
Austria	57.2	35.8	4.0	5.5	37.3
Belarus	19.2	21.8	4.2	12.7	3.5
Belgium	57.9	49.4	10.4	8.2	35.1
Bulgaria	15.2	6.0	2.0	1.0	7.8
Croatia	40.4	24.3	1.5	17.8	13.3
Czech republic	22.3	24.9	2.0	10.1	11.4
Denmark	57.5	38.3	2.9	3.9	41.3
Estonia	19.3	0.0	0.0	9.9	0.0
Finland	83.6	75.8	4.5	1.1	74.2
France	36.5	23.7	5.9	1.8	21.9
Greece	33.6	31.9	4.9	13.6	14.2
Hungary	34.1	24.9	1.3	10.8	17.5
Iceland	0.0	61.4	0.0	0.0	30.1
Italy*	36.1	26.1	3.1	7.7	
Lithuania	50.5	24.5	4.0	10.0	23.9
Montenegro	47.3	17.0	0.0	16.4	16.4
Norway	49.1	40.3	0.0	5.5	39.3
Poland	41.0	30.1	3.4	10.5	22.6
Portugal	54.2	31.7	1.9	17.3	23.5
Republic of Serbia	36.6	35.1	9.0	6.3	20.6
Romania	13.8	14.5	6.4	6.1	1.5
Russia	11.3	10.4	2.5	3.0	5.2
Slovakia	30.4	19.7	4.8	13.2	7.2
Slovenia	54.5	14.4	10.5	14.0	10.5
Spain	49.2	31.4	3.3	4.8	32.1
Sweden	56.7	41.2	4.5	3.9	40.8
Switzerland	46.1	38.4	1.7	5.1	30.5
the Netherlands	57.6	40.7	7.5	6.5	35.0
United Kingdom	61.0	41.4	7.4	14.9	22.5
Total	36.2	26.3	4.3	6.8	19.1

Table 6: % on antihypertensives or ESA among dialysis patients

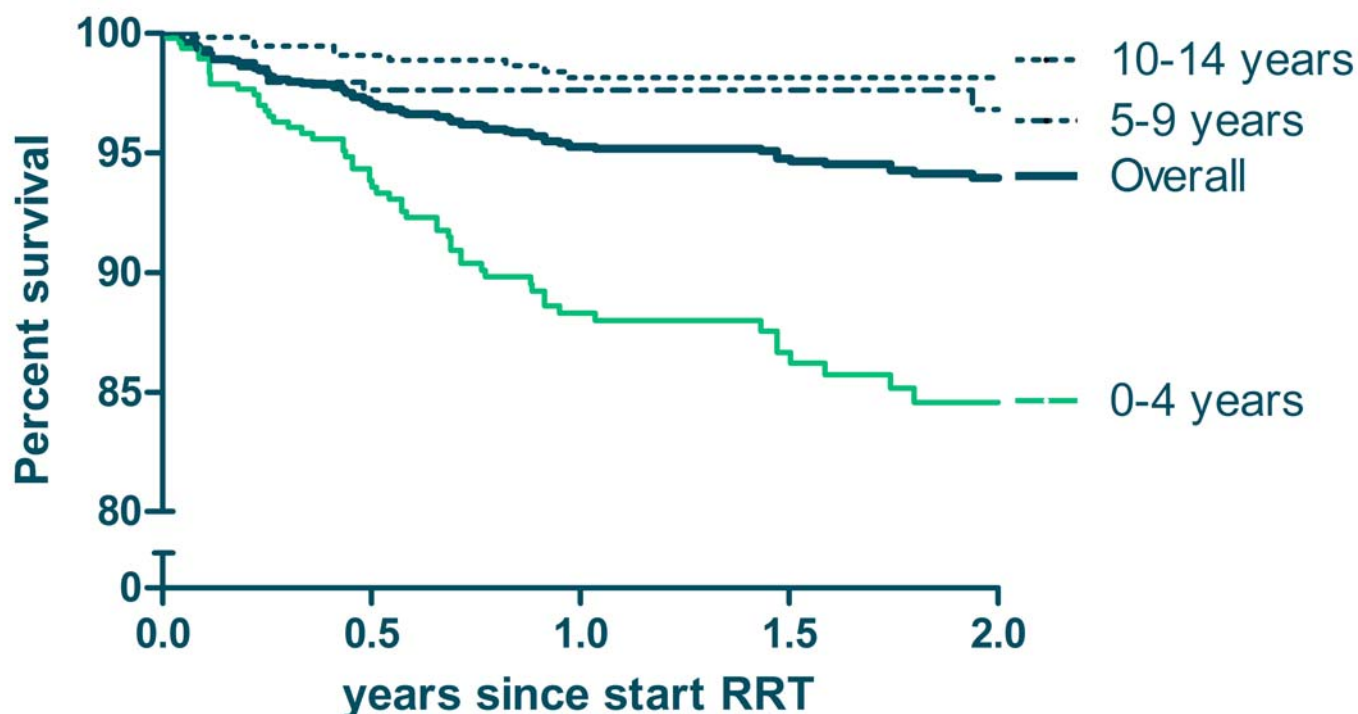
	N	percent
% on ESA	673	94.3
% on antihypertensives	438	53.4

Table 7: Number of HD sessions and duration in 2009

	N	mean	5th-95th percentile
Number of session per week	132	3.5	3 - 5
Number of hours per session	133	4.0	3 - 5

Figure 1: two-year survival

Incident RRT patients under the age of 15 starting RRT in 2007. Follow-up till 31st of December 2009.



Data included:

Austria, Belarus, Bulgaria (2008), Croatia, Czech republic, Denmark, Estonia, Finland, France, FYR of Macedonia, Greece, Hungary, Iceland, Italy, Lithuania, Montenegro, Norway, Poland, Portugal, Romania, Russia, Serbia, Slovenia, Slovakia, Spain and the Netherlands.

Table 8: Causes of Death

Causes of death according to the ERA-EDTA coding lists. Incident RRT patients under the age of 15 starting RRT in 2007. Follow-up till 31st of December 2009.

	Number of deaths	Percent
Myocardial ischemia and infarction	1	2.2
Other causes of cardiac failure	1	2.2
Cardiac arrest/sudden death other cause	4	8.7
Cerebro-vascular accident	2	4.3
Haemorrhage	3	6.5
Pulmonary infection	4	8.7
Septicaemia	10	21.7
Suicide	1	2.2
Malignant disease	4	8.7
Other identified cause of death	3	6.5
Cause of death uncertain/not determined	13	28.3

ESPN/ERA-EDTA Registry Scientific Committee

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Dieter Haffner, Germany
Jaap Groothoff, The Netherlands
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Presentations (all in the Orlando Hall) and posters during the ESPN meeting

Fri 16-09:

17.15 OS4 Variation in pediatric kidney transplantation policies and practices across Europe

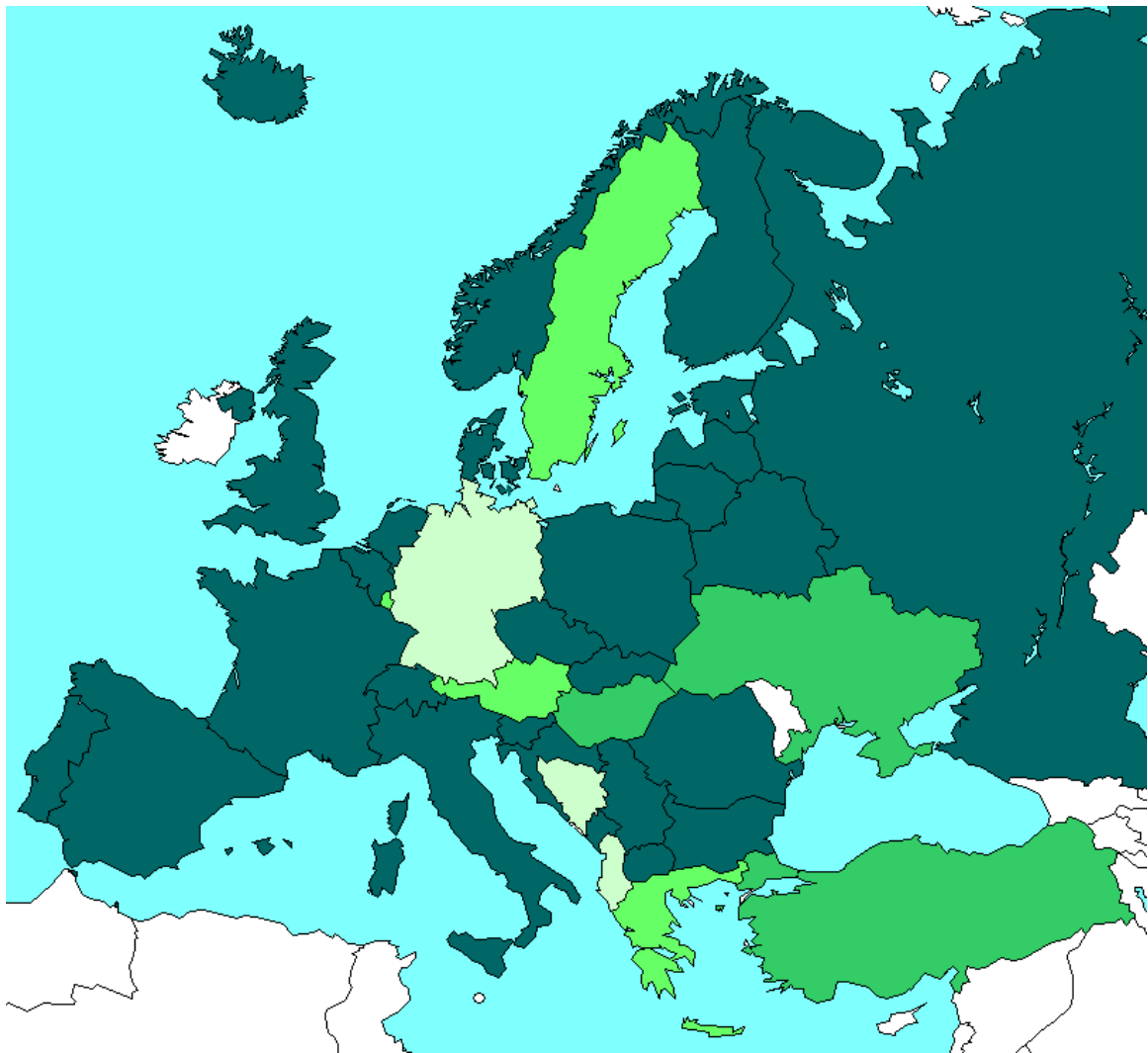
Sat17-09:

9.00 OS5 Prevalence and predictors of anaemia in children on dialysis

11.00 OS6 Outcome of chronic RRT started in the neonatal period

11.00 OS6 Impact of reference chart choice on growth interpretation and development of European height reference charts for children on RRT

Posters: PS1-THU-341, PS2-FRI-295, PS2-FRI-298, PS3-SAT-469



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

We sincerely thank the following countries and persons for their willingness to provide data

Austria	R Kramar, R Oberbauer	Lithuania	A Jankauskiene, B Pundziene
Belarus	S Baiko, A Sukalo	Montenegro	S Pavićević
Belgium	K van Hoeck, F Collart, JM des Grottes, R Lombaerts, F Janssen	Norway	T Leivestad, D Brackman, A Bjerre
Bosnia Herzegovina	D Pokrajac	Poland	A Zurowska, I Zagodzón
Bulgaria	D Roussinov	Portugal	C Mota, M Almeida, C Afonso
Croatia	Z Purić, D Batinić, Z Mustapić	Romania	G Mircescu, L Garneata,
Czech Republic	T Seeman, K Vondrak	Russia	EA Molchanova, NA Tomilina, BT Bikbov
Denmark	J Heaf	Serbia	M Kostic, A Peco-Antic, D Kruscic, D Paripovic, B Spasojevic-Dimitrijeva, G Milosevski-Lomic
Estonia	U Toots	Slovakia	L Podracka, G Kolvek
Finland	P Finne, C Grönhagen-Riska	Slovenia	N Battelino, G Novljan, J Buturovic-Ponikvar
France	C Couchoud, P Niaudet	Spain	A Alonso Melgar and the Spanish Paediatric Registry.
FYR of Macedonia	E Sahpazova	Sweden	S Schön, KG Prütz, A Seeberger
Germany	F Schaefer, G Gernsdorf, C Barth C Scholz, B Tönshoff, L Plotnicki	Switzerland	L Backman, M Herthelius, B Rippe
Greece	GA Ioannidis	The Netherlands	S Rossi, E Maurer, B Schnarwyler
Hungary	G Reusz, S Túri, L Szabó, T Szabó, Zs Györke, E Kis	Turkey	CE Kuehni, G Laube
Iceland	R Pálsson, V Edvardsson	Ukraine	A Hoitsma, A Hemke, WF Tromp, JW Groothoff, N Schoenmaker
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