

The New ESPN Registry

by Jane Tizard, Enrico Verrina, Karlijn van Stralen and Christer Holmberg



Jane Tizard and Enrico Verrina

RRT. The extended ESPN Registry collects information on incidence, survival, and quality of treatment both from the ERA-EDTA Registry and from national paediatric registries. So far, in addition to the fourteen registries contributing paediatric data via the ERA-EDTA Registry, another sixteen countries have contributed extended paediatric data directly to the ESPN Registry.

Furthermore, five more countries will provide extended paediatric data in the future and of those countries providing data via the ERA-EDTA Registry, five are extending their dataset to provide more comprehensive paediatric data. **We sincerely would like to thank all those who have helped to contribute data.**

The first results of the ESPN Registry are now available and are partly presented in this report. As numbers are large, this new ESPN Registry creates possibilities for extended research among paediatric patients on RRT. We hope that this project will improve patient care in Europe. More detailed analysis will be presented at the ESPN conference in Lyon on Friday, September 12th, during the registry symposium session at 14.50 hr.

If your country does not yet contribute data to the ESPN Registry, but is willing to do so, please let us know. There will be a registry meeting for those interested in participation in Lyon on Saturday, September 13th, at 13.00, or contact us via esn-reg@amc.uva.nl.

We are delighted to show you the first official newsletter and annual report from the new ESPN Registry. So far, the ERA-EDTA Registry has collected data on children on renal replacement therapy (RRT) via national or regional renal registries. In 2007, in close collaboration with the ERA-EDTA, the ESPN started an additional registry specifically aiming at children and young adults on

The Database

by Karlijn van Stralen

The ESPN Registry collects data on RRT on an annual basis via the national and regional renal registries in Europe.

To achieve that the same data are collected in all countries, but also to stimulate data collection, we made a prioritization of suggested data collection, based on 3 levels. First baseline or essential data, which are, as the word suggests, critical. They include a unique patient identifier as well as the treatment modality, cause of renal disease, sex, date of birth and date of first renal replacement therapy. We also would like to know changes of therapy, death and cause of death, and transfers to other countries. The

extended A and B data sets are more detailed. It might not be possible for some countries to collect these data initially, but we hope that in the future we will be collecting this detailed information.

Examples of data included in the extended A data set are comorbidities, serum creatinine levels, weight and height.

Examples of extended B data are date of first visit to a nephrologist or type of immunosuppressive agent. We would be very pleased if you would be willing to collect these data.

We have made Excel and Access databases to facilitate data collection.

Nevertheless, it is possible to merge your database with the ESPN database. Please contact us via esn-reg@amc.uva.nl to receive more information on this. Or visit us during the meeting for registries in Lyon (Saturday, September 13th, at 13.00 hr) for a demonstration.

Karlijn van Stralen



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42nd Annual Meeting ESPN

Lyon, September 11-14, 2008

t ESPN Registry symposium

Symposium 4. Presentation of ESPN results, Friday, September 12th, at 14.50 hr.

u ESPN Registry meeting

Discussion of participation in the registry and explanation of collection of variables, Saturday, September 13th, at 13.00 hr. Please check the registration desk for the location.

Data over the Year 2006

Table 1: Incident Patients

Incident paediatric patients accepted for renal replacement therapy in 2006 and general population characteristics of all the countries contributing data to the ESPN Registry.

Country	Total	General Population Characteristics		
	RRT patients 0-15 [count]	children 0-15 [count]	all 0-99 [count]	children 0-15 [%]
Austria	9	1,312,978	8,267,906	15.9
Czech Republic	10	1,490,425	10,269,147	14.5
Denmark	8	1,015,017	5,437,281	18.7
Finland	6	904,045	5,266,278	17.2
France *	40	11,738,421	63,195,466	18.6
FYR of Macedonia	0	391,301	2,039,375	19.2
Greece	6	1,595,018	11,148,465	14.3
Hungaria [§]	8	1,325,733	8,661,386	15.3
Iceland	0	65,411	303,789	21.5
Italy *	48	8,303,033	58,941,509	14.1
Lithuania	7	549,260	3,394,091	16.2
Norway	5	906,374	4,660,687	19.4
Poland	27	6,105,769	38,141,274	16.0
Portugal	11	1,640,936	10,584,353	15.5
Romania	16	3,339,093	21,587,680	15.5
Serbia	0	1,157,618	7,411,576	15.6
Slovenia	0	282,151	2,006,876	14.1
Spain, Andalusia	6	1,286,895	7,848,514	16.4
Spain, Aragon	0	163,168	1,277,471	12.8
Spain, Basque country	4	262,830	2,133,684	12.3
Spain, Catalonia [‡]	10	988,016	6,995,206	14.1
Spain, Valencia	7	694,452	4,806,908	14.4
Sweden	21	1,555,182	9,080,513	17.1
the Netherlands	26	2,971,601	16,346,112	18.2
Turkey ^{* †}	113	40,895,172	142,275,515	28.7
United Kingdom ^x	61	11,609,490	65,665,800	17.7
Total	449	102,549,389	517,746,862	19.8

* Pre-emptive transplantation patients are not included.

[†] Hungary had 86% coverage of the general population.

[‡] Spain, Catalonia provided data regarding 2005.

[†] Turkey provided data regarding 2002.

^x the United Kingdom provided data regarding 2004.

Table 2: Prevalent Patients

Prevalence of renal replacement therapy in paediatric patients in 2006. Prevalent counts and prevalence per million age related population, by age and gender.

Country	Total		Age Groups			Gender	
	RRT patients 0-15		infants 0-4	children 5-9	youngsters 10-15	men 0-15	women 0-15
	[count]	[pmp]	[pmp]	[pmp]	[pmp]	[pmp]	[pmp]
Austria	51	38.8	22.5	42.0	49.5	43.1	34.4
Czech Republic	28	18.8	12.3	17.8	25.2	19.6	17.9
Denmark	41	40.4	12.3	38.5	68.2	51.9	28.3
Finland	80	88.5	66.3	103.0	95.0	101.9	74.5
France *	193	16.4	14.0	14.3	21.2	17.8	15.0
FYR of Macedonia	4	10.2	0.0	23.6	6.7	14.9	5.3
Greece	44	27.6	7.6	33.1	41.7	38.2	24.5
Hungaria [§]	37	27.9	7.3	19.1	52.7	38.2	17.0
Iceland	3	45.9	0.0	46.8	87.8	30.0	62.4
Italy *	278	33.5	21.0	33.7	45.6	39.4	27.3
Lithuania	15	27.3	13.2	17.1	44.9	28.4	26.2
Norway	45	49.6	31.2	36.2	79.7	62.4	36.2
Poland	102	16.7	17.9	18.0	14.8	21.4	11.8
Portugal	54	32.9	18.2	33.1	47.5	38.0	27.5
Romania	33	9.9	0.9	7.2	20.4	7.6	12.3
Serbia	6	5.2	5.3	5.5	4.8	8.4	1.8
Slovenia	6	21.3	22.2	21.8	20.0	34.5	7.3
Spain, Andalusia	42	32.6	6.9	43.4	48.2	33.3	32.0
Spain, Aragon	4	24.5	18.1	0.0	54.7	23.9	25.2
Spain, Basque country	18	68.5	31.3	81.6	98.5	66.6	70.4
Spain, Catalonia [‡]	56	56.7	30.7	63.2	79.9	74.7	37.5
Spain, Valencia	28	40.3	25.2	31.2	64.7	53.2	26.7
Sweden	77	49.5	29.7	47.0	68.7	52.7	46.2
the Netherlands	124	41.7	15.3	39.9	69.6	48.0	35.1
Turkey ^{* †}	487	11.9	2.4	10.0	23.6	11.9	11.9
United Kingdom ^x	519	44.7	15.4	39.9	76.2	55.0	33.7
Total	2375	23.2	10.8	21.4	36.9	26.4	19.7

* Pre-emptive transplantation patients are not included, therefore the numbers are a slight underestimation of the true incidence and prevalence

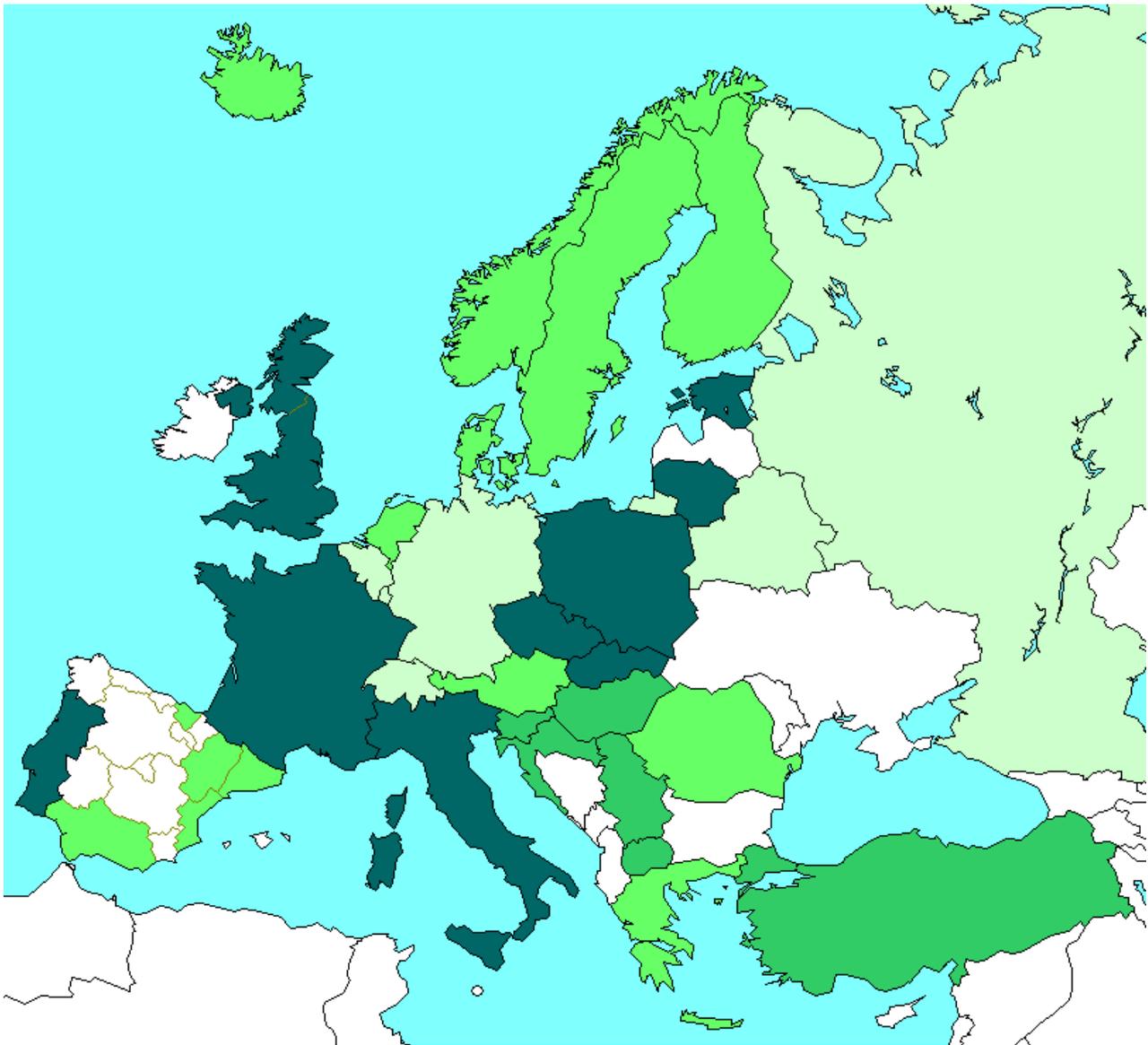
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[†] Turkey provided data regarding 2002.

^x the United Kingdom provided data regarding 2004.

To cite these numbers, please refer to the ERA-EDTA annual report, 2006 or to van der Heijden et al, *Pediatr Nephrol.* 2004



Provided extended data to the ESPN Registry

Provided limited data to the ESPN 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 to the ESPN Registry

Austria	R Kramar, R Oberbauer	Romania	L Garneata, M Gafengu, G Mitcescu
Belarus	A Sukalo, I Kazyra	Russia	E Molchanova, B Bikbov
Croatia	D Batini, Z Pureti	Serbia	A Peco-Antic, D Paripovic, M Kostic
Czech Republic	T Seeman, K Vondrak	Slovakia	L Podracka, D Kolvek
Denmark	J Heaf	Slovenia	J Buturovic-Ponikvar, G Novljan, RB Kenda
Estonia	M Ots, I Vainumäe, A Traat	Spain, Andalusia	P Castro
Finland	P Finne, C Grönhagen- Riska	Spain, Aragon	Registro de Insuficiencia Renal Crónica en Tratamiento Sustitutivo
France	P Niaudet, L Mignot	Spain, Basque country	R Alonso
FYR of Macedonia	E Sahpazova, D Kuzmanovska	Spain, Catalonia	Á Magaz, J Aranzabal, I Lampreabe, J Arrieta
Germany	C Barth, F Schaefer	Spain, Valencian region	O Zurriaga, MJ Garcia-Blasco †
Greece	GA Ioannidis	Switzerland	CE Kuehni
Hungary	G Reusz, L Szabo, T Szabo	Sweden	S Schön, J Ahlmén
Iceland	R Palsson	The Netherlands	F Scheelings, D Vandic, J Groothoff
Italy	E Verrina, D Mattucci, S Varriale	Turkey	R Topaloglu
Lithuania	A Jankauskiene	United Kingdom	M Lewis
Norway	T Leivestad		
Poland	A Zurowska, I Zagodzdon		
Portugal	H Jardim, C Mota		