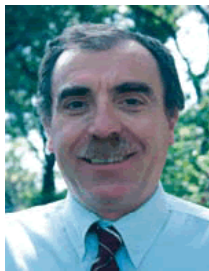


by Karlijn van Stralen, Jane Tizard, Enrico Verrina, Kitty Jager and Pierre Cochat

An update on the Registry



Jane Tizard and Enrico Verrina

As members of the ESPN/ERA-EDTA Registry committee we would like to thank you for the fantastic participation and enthusiasm for the Registry. Last year, already, many countries participated, but this year even more countries contributed with data. Currently, 29 countries have provided data, resulting in a database including a total of 4804

patients under the age of 20 who started renal replacement therapy between 1996 and 2008 who can be included in data analyses. Countries that participate in the registry are shown on the back of this leaflet. If you are interested in participating in the registry, would like to know more about the registry, or if you have questions regarding your data collection or more general questions **please visit us at the meeting for registries of the ESPN/ERA-EDTA Registry, on Saturday 13.30hr, in room Michael Tippet.**

But there is more! Last June, the first paper of the ESPN/ERA-EDTA Registry was published online in *Nephrology, Dialysis Transplantation (NDT)*. The paper describes the background

and the development of the Registry.

Secondly, the ERA-EDTA council has decided to provide a considerable extra funding to the ESPN/ERA-EDTA Registry. As a result, the number of staff on the registry can be increased from 1 to 3. This will provide time for the analysis of the data, and the writing of papers. This is a great step forward and we are very grateful to the ERA-EDTA council for making this possible.

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 results

The ESPN/ERA-EDTA Registry collects data on renal replacement therapy on an annual basis via the national and regional renal registries in Europe. So far data have been included from two subsequent years. Moreover, as some countries have a long history of (extended) data collection they have information for longer periods. These data on nearly 5000 patients can now be used for research projects.

In 2007 there was a wide variation in the number of patients treated with renal replacement therapy. The incidence ranged from 0 per million age-related population, as no patients started RRT in that year, to 15.2 per million age-related population. Be-

sides differences in incidence, the prevalence also shows a wide range from 3.2 to 95.7 per million age-related population.

Currently, besides differences in incidence and prevalence between European countries, we are also studying variation in treatment practice. A study that is in progress is concerning the timing of initiation of renal replacement therapy in children. We have studied factors determining GFR at start of treatment, adherence to the current guidelines as well as differences between regions in Europe.

The results of these studies will be presented during the ESPN/ ERA-EDTA registry symposium on Friday September 4th, at 17.30.

With our current data we can carry out many more research projects. If you are interested in performing a research project on the ESPN/ERA-EDTA registry data, please do not hesitate to contact Karlijn van Stralen: K.J.vanStralen@amc.uva.nl or visit us during one of the meetings.

Karlijn van Stralen



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43rd ESPN Annual Meeting

Birmingham, September 2-5, 2009

① Registry symposium

Symposium 4. Presentation of the ESPN/ERA-EDTA Registry results. Friday, September 4th, at 17.30 hr.

② Registry meeting

Discussion of participation in the registry and explanation of collection of variables. Saturday, September 5th, 13.30 hr. Room Michael Tippet.

Data over the Year 2007

Table 1: Incident Patients

Incident paediatric patients accepted for renal replacement therapy in 2007 and general population characteristics of countries contributing 2007 data to the ESPN/ERA-EDTA Registry.

Country	Total		General Population Characteristics		
	RRT patients 0-14 [count]	[pmp]	children 0-14 [count]	all 0-99 [count]	children 0-14 [%]
Austria	10	7.7	1,296,776	8,281,292	15.7
Croatia	2	2.9	686,967	4,419,604	15.5
Czech	9	6.1	1,478,219	10,334,157	14.3
Denmark	5	4.9	1,025,793	5,518,085	18.6
Estonia	0	0.0	199,224	1,341,672	14.8
Finland	11	12.3	897,885	5,288,716	17.0
France	77	6.5	11,767,559	63,614,000	18.5
FYR of Macedonia	3	7.9	381,868	2,042,792	18.7
Greece	13	8.1	1,598,665	11,192,762	14.3
Hungaria [§]	3	2.3	1,306,536	8,647,969	15.1
Iceland	1	15.2	65,633	310,523	21.1
Italy*	35	4.2	8,350,585	59,375,287	14.1
Latvia [‡]	1	3.2	315,386	2,276,098	13.9
Lithuania	3	5.7	527,561	3,375,618	15.6
Montenegro	0	0	123,048	626,186	19.7
Norway	3	3.3	906,655	4,709,153	19.3
Poland	41	6.9	5,961,618	38,120,558	15.6
Portugal [‡]	16	9.8	1,633,245	10,608,333	15.4
Romania	8	2.4	3,298,815	21,546,870	15.3
Russia [§]	81	7.8	10,426,340	71,057,451	14.7
Serbia	5	4.4	1,142,760	7,381,582	15.5
Slovakia	4	4.6	860,833	5,397,316	15.9
Slovenia	2	7.1	281,081	2,018,118	13.9
Spain, Andalusia	10	7.6	1,316,682	8,130,840	16.2
Spain, Aragon	2	11.7	170,569	1,311,786	13.0
Spain, Basque	1	3.7	271,786	2,149,487	12.6
Spain, Catalonia	4	3.8	1,046,915	7,210,508	14.5
Spain, Valencia	7	9.9	707,577	4,885,029	14.5
Sweden	11	7.1	1,545,660	9,148,090	16.9
the Netherlands	22	7.5	2,947,170	16,381,695	18.0
United Kingdom	83	7.7	10,721,100	60,975,700	17.6
Total	473	6.5	73,260,510	457,677,084	16.0

[§]Hungary had 86% coverage of the general population, Russia covered 50% of the population

* (Pre-emptive) transplantation patients are not included

[‡] Only patients from paediatric centres were included

Table 2: Prevalent Patients

Prevalent paediatric patients on renal replacement therapy on the 31st of December 2007. Prevalent counts and prevalence per million age related population, by age and gender of those countries contributing 2007 data to the ESPN/ERA-EDTA Registry.

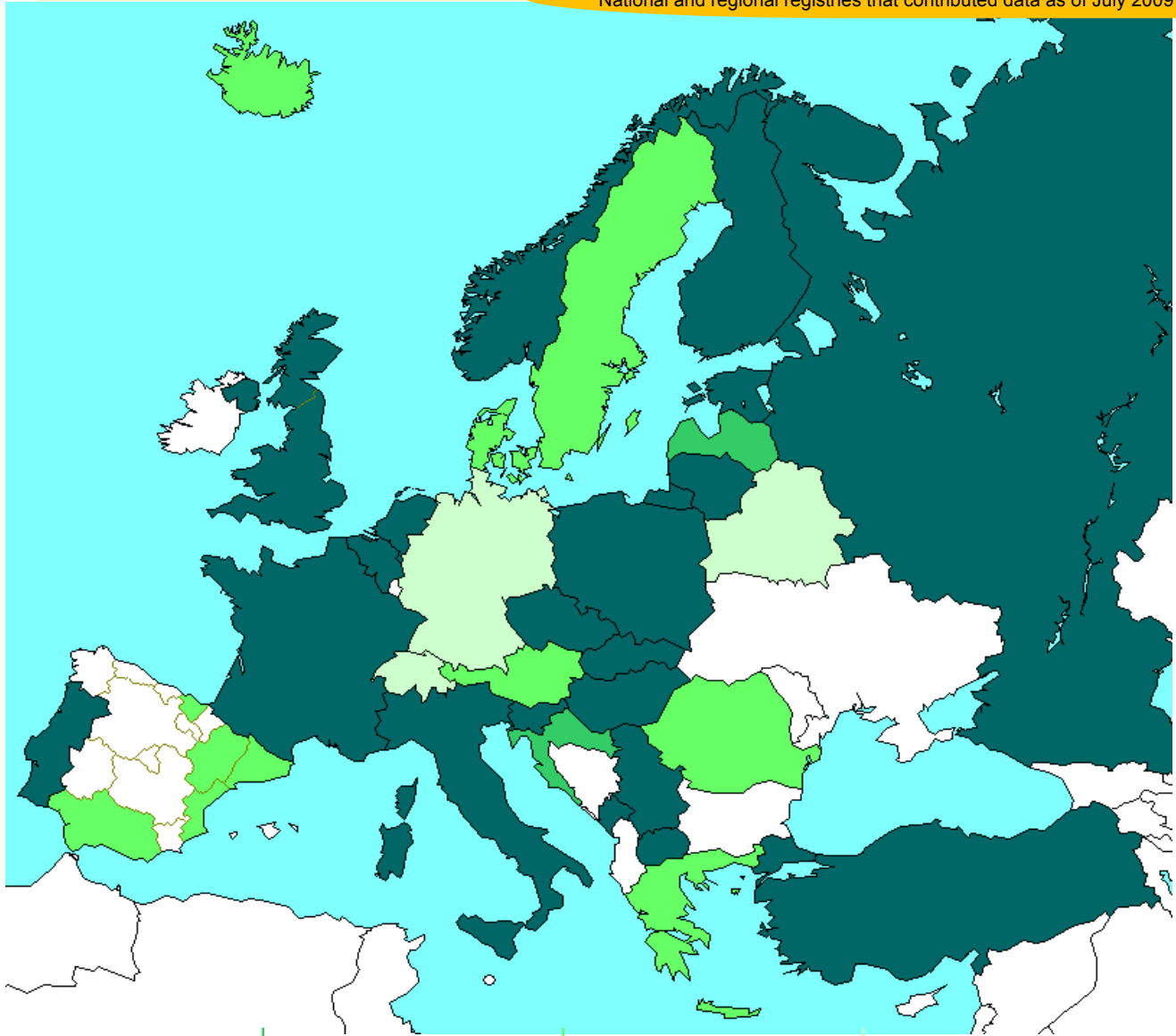
Country	Total		Age Groups			Gender	
	RRT patients 0-14 [count]	[pmp]	infants 0-4 [pmp]	children 5-9 [pmp]	adolescents 10-14 [pmp]	males 0-14 [pmp]	females 0-14 [pmp]
Austria	52	40.1	17.5	50.3	50.1	48.1	31.7
Croatia	19	27.7	14.6	17.5	47.4	31.2	23.9
Czech	33	22.3	19.8	15.5	30.7	21.1	23.6
Denmark	38	37.0	15.2	38.4	56.0	45.7	28.0
Estonia	2	10.0	0.0	16.2	14.8	9.8	10.3
Finland	83	92.4	79.3	93.8	103.0	102.5	81.9
France	402	34.2	15.5	29.3	58.2	41.8	26.1
FYR of Macedonia	7	18.3	0.0	16.1	34.6	25.4	10.8
Greece	46	28.8	9.3	33.1	43.9	34.0	23.2
Hungaria [§]	37	28.3	7.2	21.7	52.5	38.8	17.3
Iceland	2	30.5	0.0	94.1	0.0	0.0	62.1
Italy*	248	29.7	18.2	32.2	38.7	34.0	25.1
Latvia [‡]	1	3.2	0.0	0.0	8.9	6.2	0.0
Lithuania	17	32.2	19.7	23.8	48.2	44.4	19.4
Montenegro	1	8.1	0.0	24.7	0.0	15.7	0.0
Norway	41	45.2	24.0	39.9	70.0	53.8	36.2
Poland	205	34.4	18.3	35.5	46.3	41.9	26.5
Portugal [‡]	64	39.2	20.3	45.5	51.7	47.7	30.2
Romania	35	10.6	1.9	7.3	21.9	8.9	12.4
Russia [§]	168	16.1	5.5	14.0	29.1	16.3	15.9
Serbia	28	24.5	5.4	27.4	39.5	32.4	16.2
Slovakia	23	26.7	7.6	25.8	43.1	27.2	26.2
Slovenia	6	21.3	10.9	33.0	20.4	27.7	14.6
Spain, Andalusia	41	31.1	6.8	25.7	60.4	33.9	28.2
Spain, Aragon	6	35.2	34.0	17.9	53.8	45.6	24.2
Spain, Basque	26	95.7	20.0	134.0	145.5	100.3	90.8
Spain, Catalonia	46	43.9	31.0	46.9	56.5	53.8	33.5
Spain, Valencia	29	41.0	32.8	34.6	55.9	54.9	26.2
Sweden	75	48.5	30.8	44.5	68.5	55.5	41.2
the Netherlands	131	44.4	18.8	45.6	68.2	52.4	36.1
United Kingdom	553	51.6	23.4	46.7	83.4	61.0	41.1
Total	2465	33.6	16.2	32.3	51.8	39.4	27.5

[§]Hungary had 86% coverage of the general population, Russia covered 50% of the population

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

[‡] Only patients from paediatric centres were included, which may have resulted in an underestimation of the true incidence and prevalence

To cite these numbers, please refer to the ERA-EDTA annual report, 2007 or to van der Heijden et al, *Pediatr Nephrol.* 2004



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	Portugal	C Mota, M Almeida, C Afonso
Belarus	A Sukalo, I Kazyra	Romania	G Mircescu, L Garneata, E Podgoreanu, M Gafencu
Belgium	F Collart, JM des Grottes, R Lombaerts, F Janssen	Russia	EA Molchanova, NA Tomilina, BT Bikbov
Croatia	Z Purić, D Batinić, Z Mustapić	Serbia	A Peco-Antic, M Kostic, B Spasojevic-Dimitrijeva, D Paripovic
Czech Republic	T Seeman, K Vondrak	Slovakia	L Podracka, D Kolvek
Denmark	J Heaf	Slovenia	J Buturovic-Ponikvar, G Novljan, RB Kenda
Estonia	U Toots	Spain, Andalusia	P Castro de la Nuez, JM Muñoz Terol
Finland	P Finne, C Grönhagen-Riska	Spain, Aragon	Registro de Insuficiencia Renal Crónica en Tratamiento Sustitutivo
France	C Couchoud, P Niaudet, L le Mignot	Spain, Basque	A Magaz, J Aranzabal, I Pampreabe, J Arrieta
FYR of Macedonia	E Sahpazova	Spain, Catalonia	E Arcos, J Comas, R Deulofeu, J Twose
Germany	F Schaefer, C Barth, G von Gersdorff	Spain, Valencia	O Zurriaga, M Ferrer
Greece	G Ioannidis	Sweden	S Schön, J KG Prütz, A Seeberger, L Backmän, M Herthelius
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Latvia	V Strazdins, I Andersone		
Lithuania	A Jankauskiene		
Montenegro	S Pavićević		
Norway	T Leivestad		
Poland	A Zurowska, I Zagozdzon		