

by Karlijn van Stralen, 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 and enthusiasm for the Registry. This year, even more countries participated, with a current participation of 31 countries. At the moment a total of 7687 patients under the age of 20 who started RRT between 1997 and 2009 can be included in data analyses.

But there is more! This year, two papers containing data from the registry have been published. First the demographic data from last year's leaflet, as well as data on treatment modalities have been published in *Pediatric Nephrology*¹. In addition, in May the first clinical paper showing the distribution of eGFR at start of RRT has been published in *NDT*².

Secondly, this year the staff of the registry was extended. Due to a generous grant from the ERA-EDTA Council to the registry we were able to extend the working hours of the project coordinator (Karlijn van Stralen) and in March, Mark Titulaer started as the new data manager. He is currently developing a tool for internet-based data collection. In April, Marjolein Bonthuis started as a PhD student on the regis-

try. The current focus of her project is BMI. Furthermore, in February, Marijn Kramer started her internship on hypertension in children on RRT. Finally Jerome Harambat has received funding from the QUEST project for a one-year exchange project on transplantation starting November 2010.

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.

¹ Van Stralen et al. *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.*

² Van Stralen et al. *Determinants of eGFR at start of renal replacement therapy in paediatric patients, NDT. Epub ahead of print, June 2010*

Data analyses and results

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 three subsequent years.

As you probably noted, the annual report has doubled in size. Besides more extended information the incidence and prevalence, this year also information on survival and causes of death, as well as on clinical parameters such as eGFR at start of RRT and use of EPO are presented.

In 2008 there was a wide variation in incidence and prevalence, ranging from 0 per million age-related population, as no patients started RRT in that year, to

Besides differences in incidence, the prevalence also shows a wide range from 3.2-76.2 per million age-related population. Two-year survival was 95.6% after start of RRT. The most important causes of death were infections and cardiovascular events.

In the upcoming year, we have plans for numerous publications. Papers on anemia in transplant and dialysis patients, as well as the one on hypertension are currently being finalized. The next analyses will concern specific patient populations with rare disorders.

At the IPNA meeting we will present posters on hypertension and anemia in children on RRT as well as on eGFR at start of RRT.

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 the IPNA conference or one of the meetings.

Karlijn van Stralen



Table 1: Incident patients

Incident paediatric patients accepted for renal replacement therapy in 2008 and general population characteristics of countries contributing 2008 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	6	4.4	1,366,129	8,331,930	16.4
Belarus	8	5.6	1,418,306	9,680,843	14.7
Belgium	6	3.3	1,800,455	10,666,866	16.9
Croatia	6	8.8	681,287	4,416,521	15.4
Czech republic	5	3.4	1,478,467	10,424,342	14.2
Denmark	7	6.8	1,022,667	5,550,989	18.4
Estonia	1	5.0	199,533	1,340,515	14.9
Finland	3	3.4	892,878	5,313,400	16.8
France	64	5.4	11,825,540	64,005,000	18.5
FYR of Macedonia	0	0.0	373,851	2,046,229	18.3
Greece	12	7.5	1,607,098	11,237,094	14.3
Hungary	3	2.0	1,500,703	10,038,183	14.9
Iceland	0	0.0	66,282	317,415	20.9
Italy*	36	4.3	8,405,498	59,832,179	14.0
Latvia	0	0.0	311,310	2,266,093	13.7
Lithuania	1	2.0	510,967	3,358,116	15.2
Montenegro	3	24.5	122,276	628,801	19.4
Norway	6	6.6	909,796	4,768,211	19.1
Poland	39	6.6	5,865,158	38,125,758	15.4
Portugal	13	8.0	1,625,921	10,622,413	15.3
Republic of Serbia	13	11.5	1,127,901	7,350,220	15.3
Romania	17	5.2	3,271,558	21,513,622	15.2
Russia	71	3.4	20,958,324	141,956,409	14.8
Slovakia	3	3.6	843,557	5,406,628	15.6
Slovenia	4	14.2	282,225	2,021,315	14.0
Spain	50	7.4	6,736,885	46,451,812	14.5
Sweden	10	6.5	1,542,066	9,219,635	16.7
Switzerland	6	5.1	1,178,255	7,647,676	15.4
the Netherlands	24	8.2	2,929,392	16,445,591	17.8
Ukraine [‡]	11	1.7	6,488,640	46,077,834	14.1
United Kingdom	82	7.6	10,753,600	61,383,200	17.5
Total	510	5.2	98,096,525	628,444,840	15.6

Table 2: Treatment modality at start of RRT

Treatment modality at day 1, among patients < 15 years of age, starting RRT in 2008

	N	percent	pmarp
HD at start	177	36.1	1.9
PD at start	239	48.8	2.6
Pre-emptive transplantation	74	15.1	0.8

Table 3: PRD distribution at start of RRT

Treatment modality at day 1, among patients < 15 years of age, starting RRT in 2008

	N	percent	pmarp
Glomerulonephritis	76	15.2	0.83
Congenital anomalies of the kidney and urinary tract	176	35.3	1.92
Cystic Kidney disease	59	11.8	0.64
Hereditary Nephropathy	36	7.2	0.39
Ischaemic renal failure	11	2.2	0.12
Haemolytic uraemic syndrome	29	5.8	0.32
Metabolic Disorders	17	3.4	0.19
Vasculitis	14	2.8	0.15
Pyelonephritis	6	1.2	0.07
Miscellaneous	38	7.6	0.42
Unknown	37	7.4	0.40

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 2008.

	N	percent
eGFR<8 ml min ⁻¹ per 1.73 m ²	44	22.5
eGFR 8- 15 ml min ⁻¹ per 1.73 m ²	94	48.0
eGFR>15 ml min ⁻¹ per 1.73 m ²	58	29.6

Table 5: Prevalent Patients

Prevalent paediatric patients on renal replacement therapy on the 31st of December 2008. Prevalent counts and prevalence per million age related population, by age groups of those countries contributing 2008 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	54	39.5	17.7	38.4	57.9
Belarus	26	18.3	12.6	13.3	28.5
Belgium	103	57.2	15.0	57.6	98.4
Croatia	20	29.4	14.4	27.4	43.3
Czech Republic	31	21.0	18.9	15.3	28.5
Denmark	41	40.1	27.2	32.7	59.0
Estonia	3	15.0	0.0	31.9	15.7
Finland	71	79.5	75.0	80.3	83.1
France	360	30.4	10.9	27.5	53.5
FYR of Macedonia	6	16.0	0.0	8.3	35.8
Greece	49	30.5	12.7	25.2	53.7
Hungary	31	20.7	8.2	18.7	33.7
Iceland	2	30.2	0.0	46.9	44.6
Italy*	266	31.6	20.5	34.3	40.2
Latvia	1	3.2	0.0	0.0	9.7
Lithuania	17	33.3	19.2	18.6	56.7
Montenegro	4	32.7	77.2	0.0	23.2
Norway	39	42.9	6.8	53.5	66.7
Poland	204	34.8	16.7	38.6	47.0
Portugal	69	42.4	24.4	41.4	61.4
Republic of Serbia	38	33.7	19.4	18.9	60.7
Romania	40	12.2	2.8	7.4	25.9
Russia	206	9.8	3.4	9.3	17.4
Slovakia	22	26.1	11.1	18.9	45.3
Slovenia	10	35.4	20.9	55.3	31.2
Spain	266	39.5	18.9	39.2	62.7
Sweden	68	44.1	22.6	45.6	64.3
Switzerland	52	44.1	16.1	49.5	64.0
the Netherlands	134	45.7	16.0	45.5	74.5
Ukraine [‡]	15	2.3	NA	NA	NA
United Kingdom	554	51.5	26.2	43.3	84.7
Total	2802	28.6	14.3	28.9	48.2

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

‡ Only information on age in years, and year of (changes in) RRT was available. Therefore patients were excluded from the age-group specific analyses

Table 5: Prevalent Patients (continued)

Prevalent paediatric patients on renal replacement therapy on the 31st of December 2008. Prevalent counts and prevalence per million age related population, by gender and treatment modality of those countries contributing 2008 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	47.2	31.5	1.5	2.2	35.9
Belarus	16.5	20.3	5.6	12.7	0.0
Belgium	66.3	47.7	7.8	7.2	42.2
Croatia	37.2	21.1	0.0	13.2	14.7
Czech Republic	19.8	22.2	0.7	10.1	10.1
Denmark	51.5	28.1	4.9	2.0	33.2
Estonia	19.5	10.3	0.0	10.0	5.0
Finland	83.3	75.5	1.1	2.2	76.2
France	37.0	23.6	4.1	1.7	23.8
FYR of Macedonia	25.9	5.5	0.0	16.0	0.0
Greece	35.0	25.7	5.6	12.4	12.4
Hungary	28.6	12.3	0.0	4.7	16.0
Iceland	0.0	61.6	0.0	0.0	30.2
Italy*	35.6	27.4	4.3	8.0	NA
Latvia	6.3	0.0	0.0	3.2	0.0
Lithuania	45.8	20.1	7.8	7.8	17.6
Montenegro	47.3	17.0	0.0	24.5	8.2
Norway	49.4	36.0	3.3	1.1	38.5
Poland	40.9	28.3	3.8	9.7	21.3
Portugal	51.6	32.8	2.5	14.1	24.6
Republic of Serbia	39.7	27.4	8.0	5.3	20.4
Romania	11.3	13.2	5.2	5.8	1.2
Russia	10.3	9.3	2.6	3.1	4.1
Slovakia	30.1	21.9	7.1	10.7	8.3
Slovenia	55.2	14.6	14.2	14.2	7.1
Spain	46.2	32.4	2.7	4.5	31.8
Sweden	49.3	38.6	3.2	1.9	38.9
Switzerland	46.2	42.0	3.4	5.9	28.9
the Netherlands	50.0	41.2	6.5	5.1	34.1
Ukraine [‡]	2.4	2.2	1.4	0.3	0.6
United Kingdom	61.2	40.8	6.9	12.4	24.5
Total	33.1	23.7	3.8	5.9	17.7

Table 6: Use of erythropoietin in 2008

	N	Percent on EPO
Dialysis patients	638	95.1
Transplant patients	673	15.6

Table 7: Number of HD sessions and duration in 2008

	N	mean	5th-95th percentile
Number of session per week	106	3.2	2 - 5
Number of hours per session	103	3.7	2.5 – 4.5

Figure 1: two-year survival

Incident RRT patients under the age of 15 starting RRT in 2006 or 2007. Follow-up till 31st of December 2008 or 2009.



Data included:

2006-2007: Austria, Croatia, Czech republic, Denmark, Finland, France, FYR of Macedonia, Greece, Hungary, Iceland, Italy, Lithuania, Norway, Poland, Portugal, Romania, Serbia, Slovenia, Spain, the Netherlands, United Kingdom.

2007: Belarus, Estonia, Latvia, Montenegro, Russia or Slovakia

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 2006 or 2007. Follow-up till 31st of December 2008 or 2009.

	Number of deaths	percent
Heart failure	6	12.2
Cardiac arrest/sudden death other cause or unknown	7	14.3
Cerebro-vascular accident	2	4.1
Infection	10	20.4
Suicide/ refusal treatment	1	2.0
Withdrawal	3	6.1
Malignancies	4	8.2
Miscellaneous	10	20.4
Unknown	6	12.2

ESPN/ERA-EDTA Registry

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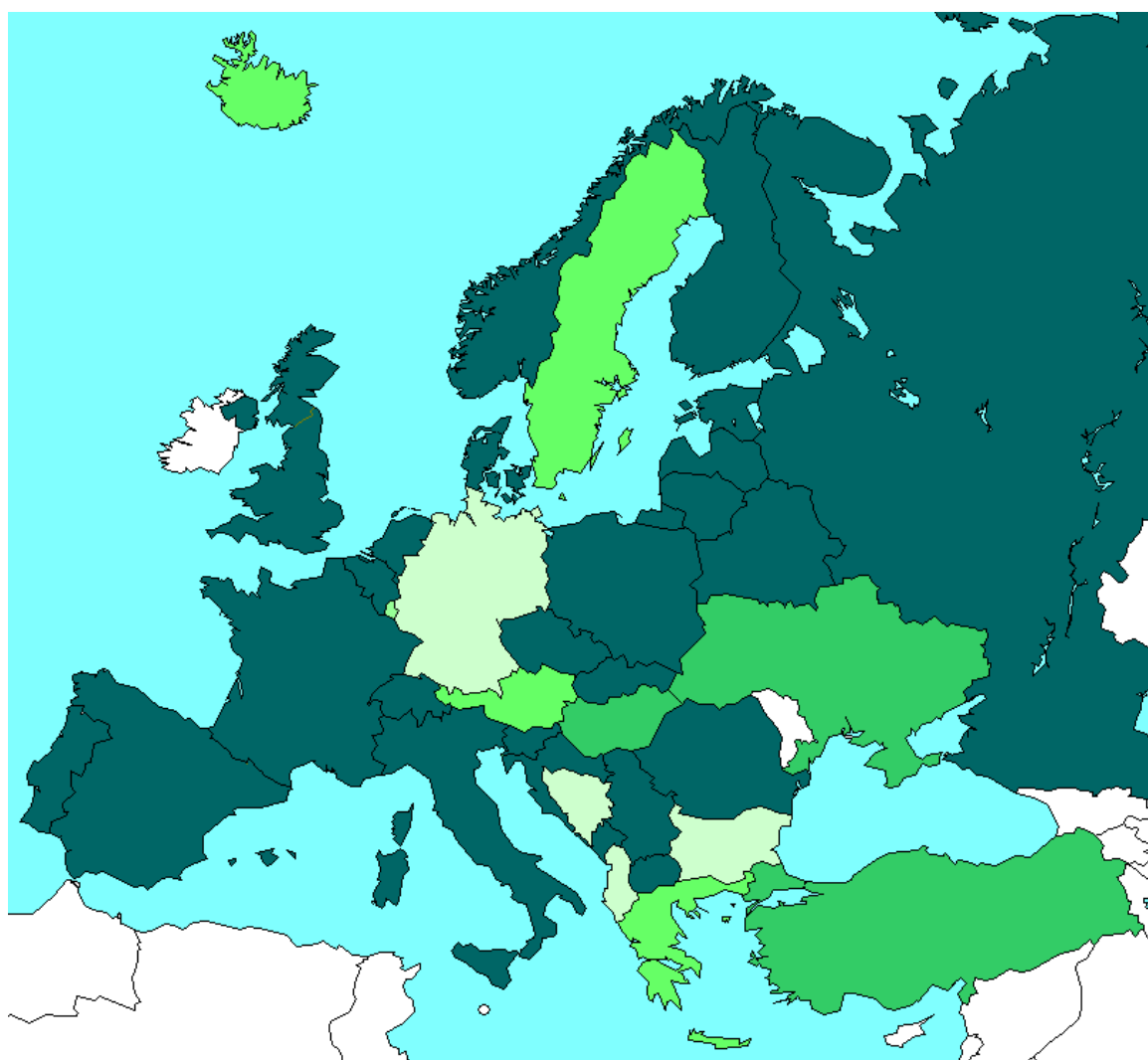
ESPN/ERA-EDTA Registry

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Presentations and posters during the IPNA meeting, Wednesday, September 1st

11.30 oral poster presentation Marijn Kramer, hypertension in pediatric RRT in Europe
Poster session (#735) - The Prevalence and Predictors of Anaemia in European Children with ERF
Poster session (#765) - Determinants of eGFR at Start of Renal Replacement Therapy in Children
Poster session (#774) - Hypertension in Pediatric Renal Replacement Therapy Patients in Europe



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

Albania	D Shitza	Lithuania	A Jankauskiene
Austria	R Kramar, R Oberbauer	Montenegro	S Pavičević
Belarus	S Baiko, A Sukalo	Norway	T Leivestad, D Brackman
Belgium	K van Hoeck, F Collart, JM des Grottes, R Lombaerts, F Janssen	Poland	A Zurowska, I Zagodzdon
Bosnia Herzegovina	D Pokrajac	Portugal	C Mota, M Almeida, C Afonso
Bulgaria	D Roussinov	Romania	G Mircescu, L Garneata, E Podgoreanu, M Gafencu
Croatia	Z Puretić, D Batinić	Russia	EA Molchanova, NA Tomilina, BT Bikbov
Czech Republic	T Seeman, K Vondrak	Serbia	A Peco-Antic, M Kostic, B Spasojevic-Dimitrijeva, D Paripovic
Denmark	J Heaf	Slovakia	L Podracka, G Kolvek
Estonia	U Toots	Slovenia	J Buturovic-Ponikvar, G Novljan, N Battelino
Finland	P Finne, C Grönhagen-Riska	Spain	A Alonso Melgar and the Spanish Pediatric Registry.
France	C Couchoud, P Niaudet, L le Mignot	Sweden	S Schön, J KG Prütz, A Seeberger, L Backmän, M Herthelius
FYR of Macedonia	E Sahpazova	Switzerland	CE Kuenhi, E Maurer
Germany	F Schaefer, G Gersdorf, C Scholz, G Ioannidis	The Netherlands	A Hoitsma, A Hemke, WF Tromp, JW Groothoff, N Schoenmaker
Greece	G Reusz, S Túri, L Szabó, T Szabó, Zs Györke, E Kis	Turkey	R Topaloglu
Hungary	R Palsson, V Edvardsson	Ukraine	D Ivanov
Iceland	Y Frishberg, N Meishish	United Kingdom	D Ansell, C Inward, M Lewis
Israel	E Verrina, S Varriale		
Italy	V Strazdins, I Andersone		
Latvia			