

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 34 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! The ERA-EDTA

council was so kind to renew the grant of the ESPN/ERA-EDTA Registry making it possible to continue with the Registry till at least 2016. This would not have been possible without all your efforts.

Like last year many visiting researchers came to the AMC. Jerome Harambat from Bordeaux (France) finalized his internship in November after working for a year for the registry. He received a grant from the QUEST project and is working on four projects within the Registry. In December and January Huib de Jong, a paediatric nephrologist from the Netherlands came to the AMC for several short periods. In January Danilo Lofaro, a medical informatician from Padova, Italy, started a 6-month in-

ternship on graft failure using registry data. All will present their results during the ESPN congress.

If you are interested in performing a research project on the registry or would like to know more about participating in the ESPN/ERA-EDTA registry, please speak to us during the ESPN conference, come and visit us during the meeting for Registries (Saturday, September 8, 1 pm) or contact Karlijn van Stralen: 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 five subsequent years.

In 2010, the median incidence was 5.6 per million age-related population (pmarp) and ranged from 0, as no patients started RRT in that year, to 12.2 pmarp. The prevalence also shows a wide range from 4.0 to 81.1 pmarp. Two-year survival was 93.4% after start of RRT. The most important cause of death was infection related. Enrico Verrina will present detailed results from the annual report during the Registry symposium on Thursday, 2 pm.

Three papers have been accepted and published in the previous months.

cJASN has accepted the paper on oxalosis in children on renal replacement therapy¹, and NDT accepted our paper on anemia in dialysis patients.² Finally, a paper on growth reference curves was published in PLoS ONE,³ and three more papers are under review at various journals.

During the ESPN conference, you will hear more results of the registry. Karlijn van Stralen will give an overview of all published papers so far, while Franz Schaefer and Jérôme Harambat will present two individual studies during the registry symposium. Besides the presentations by Danilo Lofaro and Huib de Jong, Marjolein Bonthuis will present the study on the lipid profile. **Thank you all for making this possible.**

Publication list ESPN/ERA-EDTA registry 2012

1. *Characteristics and outcomes of children with primary oxalosis requiring renal replacement therapy.* Harambat J, van Stralen KJ, Espinosa L, Groothoff JW, Hulton SA, Cerkauskiene R, Schaefer F, Verrina E, Jager KJ, Cochat P; Clin J Am Soc Nephrol. 2012;7:458-65.

2. *Prevalence and predictors of the sub-target Hb level in children on dialysis.* van Stralen KJ, Krischock L, Schaefer F, Verrina E, Groothoff JW, Evans J, Heaf J, Ivanov D, Kostic M, Maringhini S, Podracká L, Printza N, Pundziene B, Reusz GS, Vondrak K, Jager KJ, Tizard EJ. NDT 2012.

3. *Use of National and International Growth charts for studying height in European children: development of up-to-date European Height-for-age charts.* Bonthuis M., van Stralen KJ, Verrina E, Edefonti A, Molchanova EA, Hokken-Koelega ACS, Schaefer F, Jager KJ. PLoSOne 7: e 42506

4. *Epidemiology of chronic kidney disease in children.* Harambat J, van Stralen KJ, Kim JJ, Tizard EJ. Pediatr Nephrol. 2012;27:363-73.

Table 1: Incident patients

Incident paediatric patients accepted for renal replacement therapy in 2010 and general population characteristics of countries contributing 2010 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	
Albania	2	2.7	747,436	3,194,417	23.4
Austria	5	4.0	1,239,816	8,389,772	14.8
Belarus	7	4.9	1,415,055	9,671,912	14.6
Belgium	12	6.5	1,844,382	10,895,586	16.9
Bulgaria	4	3.9	1,029,320	7,534,289	13.7
Croatia	3	4.5	669,634	4,399,754	15.2
Czech republic	7	4.6	1,506,256	10,519,791	14.3
Denmark	6	5.9	1,010,963	5,604,224	18.0
Estonia	0	0.0	204,237	1,340,036	15.2
Finland	7	7.9	888,001	5,363,351	16.6
France	67	5.6	11,889,369	64,402,708	18.5
FYR of Macedonia	1	2.8	361,214	2,054,490	17.6
Germany*	22	3.6	10,981,917	81,776,929	13.4
Greece	7	4.3	1,625,462	11,307,503	14.4
Hungary	5	3.4	1,467,033	10,000,023	14.7
Iceland	0	0.0	66,543	318,041	20.9
Italy*	24	2.8	8,495,597	60,483,486	14.0
Lithuania	0	0.0	493,597	3,286,820	15.0
Malta	0	0.0	64,138	415,995	15.4
Norway	4	4.3	919,717	4,889,252	18.8
Poland	40	6.9	5,770,641	38,183,683	15.1
Portugal	9	5.6	1,612,175	10,637,346	15.2
Romania	14	4.3	3,257,994	21,480,400	15.2
Russia	72	3.4	21,246,520	141,909,244	15.0
Serbia	3	2.7	1,102,262	7,291,436	15.1
Slovakia	3	3.6	830,888	5,430,099	15.3
Slovenia	3	10.4	289,064	2,048,582	14.1
Spain	39	5.6	6,975,259	47,105,762	14.8
Sweden	19	12.2	1,557,200	9,378,126	16.6
Switzerland	4	3.4	1,186,018	7,827,970	15.2
the Netherlands	22	7.6	2,909,993	16,615,395	17.5
Turkey*	153	8.1	18,868,957	73,142,150	25.8
Ukraine	6	0.9	6,489,775	45,690,385	14.2
United Kingdom	83	7.6	10,871,700	62,262,200	17.5
Total*	631	5.3	118,906,216	713,074,228	16.7

* Data from Germany are based on transplantation patients only, therefore, the numbers are underestimation of the true incidence and Germany was excluded in the calculation of the overall incidence. The coverage was 12 out of 20 centers. (pre-emptive) transplantation patients are not included in the patients from Italy and Turkey, therefore the numbers are an underestimation of true incidence. Data for Turkey are based on those aged 0 – 15y.

Table 2: Treatment modality at start of RRT

Treatment modality at day 1, among patients < 15 years of age starting RRT in 2010. All patients from Germany were excluded, while patients with a pre-emptive transplantation from Italy and Turkey were excluded.

	N	percent	pmarp
HD at start	199	32.2	1.67
PD at start	327	53.1	2.75
Pre-emptive transplantation	90	14.6	0.98

Table 3: PRD distribution at start of RRT

Cause of renal failure, among patients < 15 years of age, starting RRT in 2010

	N	percent	pmarp
Glomerulonephritis	83	14.6	0.78
Congenital anomalies of the kidney and urinary tract	197	35.1	1.86
Cystic kidney disease	57	10.2	0.54
Hereditary Nephropathy	26	4.6	0.25
Ischemic renal failure	9	1.6	0.08
HUS	26	4.6	0.25
Metabolic Disorders	20	3.6	0.19
Vasculitis	6	1.1	0.06
Pyelonephritis	11	2.0	0.10
Miscellaneous	56	10.0	0.53
Unknown	71	12.7	0.67

Table 4: eGFR at start of RRT

Estimated GFR based on age, height and serum creatinine levels, calculated according to the new Schwartz formula, among incident patients, age <15 years in 2010

	N	percent
eGFR<8 ml min ⁻¹ per 1.73 m ²	33	22.9
eGFR 8- 15 ml min ⁻¹ per 1.73 m ²	70	48.6
eGFR>15 ml min ⁻¹ per 1.73 m ²	41	28.5

Table 5: Prevalent Patients

Prevalent paediatric patients on renal replacement therapy on the 31st of December 2010. Prevalent counts and prevalence per million age related population, by age groups.

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
Albania	3	4.0	4.4	0.0	7.3
Austria	51	41.1	35.6	32.0	54.5
Belarus	30	21.2	8.2	20.0	35.4
Belgium	91	49.3	22.0	56.7	70.6
Bulgaria	12	11.7	2.7	5.9	28.2
Croatia	20	29.9	18.7	19.3	48.4
Czech republic	36	23.9	8.7	41.8	24.1
Denmark	48	47.5	27.3	27.0	86.2
Estonia	1	4.9	0.0	15.2	0.0
Finland	72	81.1	56.7	107.4	80.1
France	412	34.7	14.2	34.9	55.0
FYR of Macedonia	7	19.4	8.8	8.5	38.4
Germany*	125	20.5	13.7	21.4	25.4
Greece	52	32.0	19.2	24.6	53.3
Hungary	37	25.2	8.2	22.8	44.1
Iceland	2	30.1	0.0	47.0	45.8
Italy*	257	30.3	17.2	30.7	43.0
Lithuania	13	26.3	12.1	20.1	44.9
Malta	4	62.4	49.3	49.4	84.7
Norway	36	39.1	9.8	60.4	47.6
Poland	234	40.6	21.2	40.4	59.7
Portugal	75	46.5	27.2	43.3	68.2
Romania	35	10.7	3.7	9.4	18.9
Russia	255	12.0	4.5	10.2	22.7
Serbia	33	29.9	11.5	23.5	53.6
Slovakia	22	26.5	3.5	23.1	52.2
Slovenia	18	62.3	28.7	22.0	138.8
Spain	280	40.1	18.6	38.1	66.7
Sweden	83	53.3	37.8	47.1	77.2
Switzerland	50	42.2	12.9	49.7	62.3
the Netherlands	136	46.7	27.1	42.2	69.6
Turkey*	605	32.1	17.5	24.3	53.1
Ukraine	27	4.2	0.8	1.5	10.4
United Kingdom	608	55.9	27.2	53.1	89.7
Total*	3645	30.7	14.9	28.5	46.6

* Data from Germany are based on transplantation patients only, therefore, the numbers are underestimation of the true prevalence. The coverage was 12 out of 20 centers. (pre-emptive) Transplantation patients are not included in the patients from Italy, therefore the numbers are an underestimation of true prevalence. Data for Turkey are based on the population 0 - 15; 0-5 years, 6-10 years and 11-15 years.

Table 5: Prevalent Patients (continued)

Prevalent paediatric patients on renal replacement therapy on the 31st of December 2010. Prevalent counts and prevalence per million age related population, by gender and treatment modality.

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
Albania	2.6	5.6	4.0	0.0	0.0
Austria	53.5	28.1	0.8	3.2	37.1
Belarus	16.5	26.2	3.5	8.5	8.5
Belgium	53.0	45.5	6.0	8.1	31.4
Bulgaria	17.0	6.0	5.8	1.0	4.9
Croatia	34.9	24.5	1.5	14.9	13.4
Czech republic	24.6	23.2	1.3	8.6	13.9
Denmark	59.9	34.5	2.0	3.0	41.5
Estonia	9.5	0.0	0.0	4.9	0.0
Finland	86.0	76.0	3.4	6.8	70.9
France	41.4	27.6	4.0	2.3	27.7
FYR of Macedonia	26.8	11.4	2.8	16.6	0.0
Germany*	27.5	13.1			16.5
Greece	34.6	29.2	5.5	12.3	12.9
Hungary	27.9	22.4	3.4	12.3	9.5
Iceland	0.0	61.4	0.0	15.0	15.0
Italy*	35.9	24.2	2.9	7.3	
Lithuania	27.7	24.9	4.1	6.1	16.2
Malta	60.8	64.0	0.0	0.0	62.4
Norway	44.6	33.4	0.0	2.2	37.0
Poland	46.9	31.3	3.1	9.4	26.9
Portugal	58.1	34.3	1.9	16.7	27.9
Romania	10.2	11.4	4.0	5.8	0.9
Russia	13.5	10.4	2.4	3.7	5.7
Serbia	30.0	29.9	7.3	3.6	19.1
Slovakia	30.5	22.2	3.6	14.4	8.4
Slovenia	94.1	28.5	13.8	13.8	34.6
Spain	49.1	30.7	4.7	3.4	30.1
Sweden	63.8	42.2	3.2	7.7	41.7
Switzerland	44.3	39.9	2.5	3.4	32.9
the Netherlands	59.1	33.8	4.5	6.2	36.1
Turkey*	35.4	28.5	3.2	18.1	10.8
Ukraine	3.9	4.4	2.9	0.2	1.1
United Kingdom	65.8	45.6	4.3	8.3	42.4
Total*	35.4	24.5	3.4	7.5	19.2

* Data from Germany are based on transplantation patients only, therefore, the numbers are underestimation of the true prevalence. The coverage was 12 out of 20 centers. (pre-emptive) Transplantation patients are not included in the data from Italy, therefore the numbers are an underestimation of true prevalence. Data for Turkey are based on the population 0 - 15; 0-5 years, 6-10 years and 11-15 years.

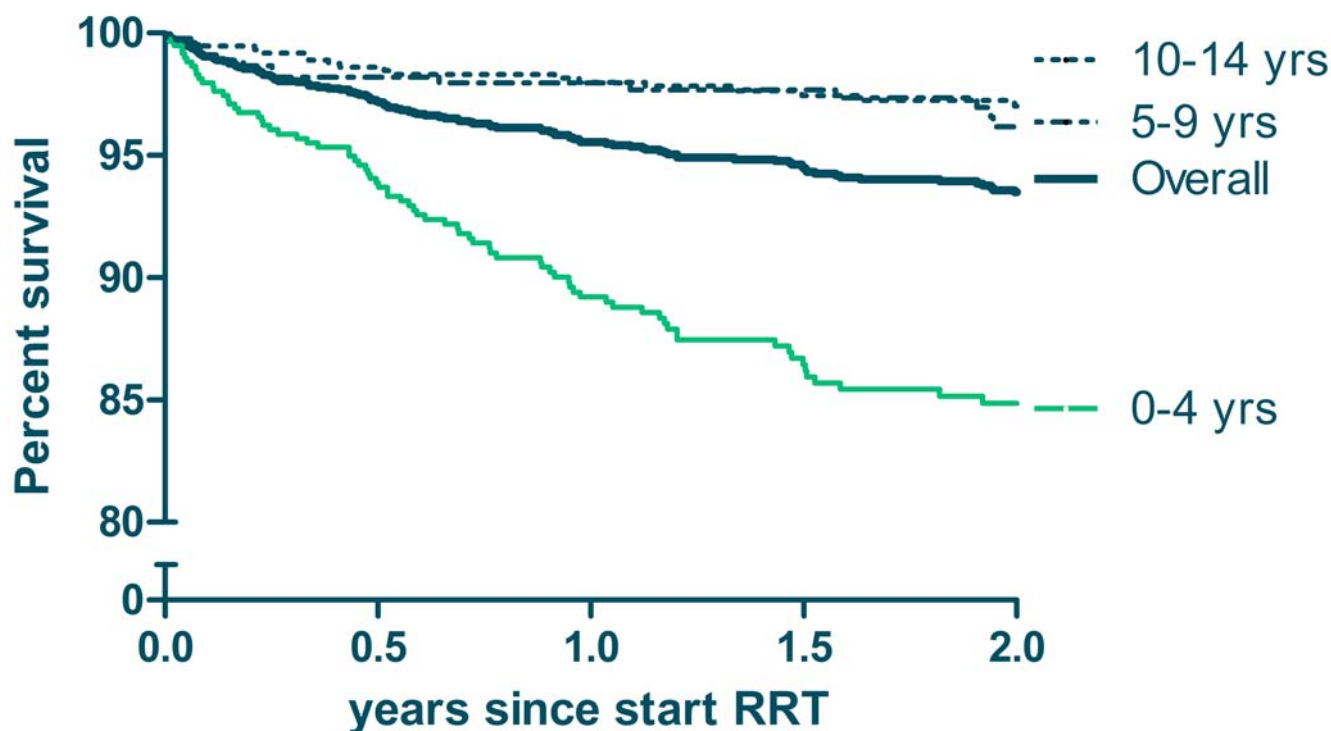
Table 6: hypertension and height in children on RRT

Height z-score based on recent national reference charts, or, if unavailable, on newly developed reference charts for Northern and Southern Europe (Bonthuis et al, PLoS ONE 7(8): e42506. doi:10.1371/journal.pone.0042506).

	Dialysis	Transplantation
Blood pressure		
% of patients with hypertension	49.1	25.9
Mean z-score systolic blood pressure	1.41	0.76
Mean z-score diastolic blood pressure	1.14	0.48
Height		
% of patients with a height z-score below 2	56.0	40.0
Mean height z-score	-2.47	-1.74

Figure 1: two-year survival

Incident RRT patients under the age of 15 starting RRT in 2007. Follow-up till 31st of December 2010.



Data included:

Austria, Belarus, Belgium, Bulgaria (2008), Croatia, Czech republic, Denmark, Estonia, Finland, France, FYR of Macedonia, Greece, Hungary, Iceland, Italy, Lithuania, Malta (2010), Norway, Poland, Portugal, Romania, Russia, Serbia, Slovenia, Slovakia, Spain, the Netherlands and the United Kingdom.

Table 7: 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 2010.

	Number of deaths	Percent
Cardiac failure	9	8.4
Cardiac arrest/sudden death other cause	6	5.6
Cerebro-vascular accident	9	8.4
Infection	23	21.5
Suicide /refusal treatment	1	0.9
Malignant disease	4	3.7
Other identified cause of death	10	9.3
Cause of death uncertain/not determined	45	42.1

ESPN/ERA-EDTA Registry Scientific Committee

Enrico Verrina, Italy *
Franz Schaefer, Germany *
Pierre Cochat, France
Rosanna Coppo, Italy
Dieter Haffner, Germany
Jaap Groothoff, The Netherlands
Jérôme Harambat, France
Kitty Jager, The Netherlands
* ESPN representatives on the ERA-EDTA Registry Committee

ESPN/ERA-EDTA Registry Staff

Karlijn van Stralen
Marjolein Bonthuis
Mark Titulaer

ESPN/ERA-EDTA Registry

Department of Medical Informatics
Academic Medical Center
room J1B-125
1105 AZ Amsterdam
The Netherlands

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Presentations and meetings during the ESPN meeting

Thursday September 6 – 14.00 - Registry symposium

Annual report - Enrico Verrina
Epidemiology of CAKUT in RRT - Franz Schaefer
Results from the ESPN/ERA-EDTA registry studies - Karlijn Van Stralen
Pediatric kidney transplantation activity and practices across Europe - Jérôme Harambat

Friday September 7 – 11.50 – Oral communications

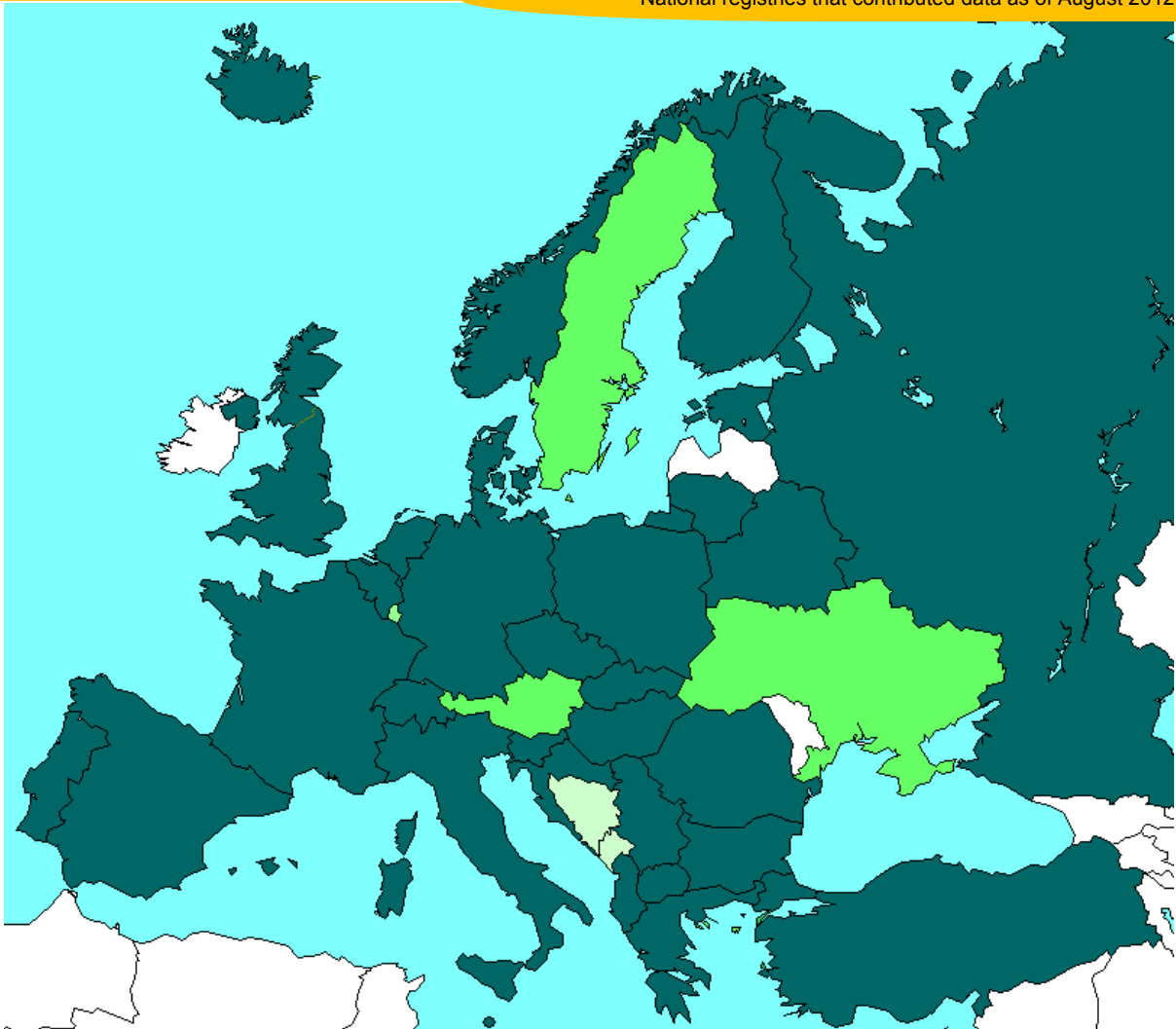
Session 1 – Dyslipidaemia in children with end-stage renal disease – Marjolein Bonthuis
Session 3 – Kidney transplantation in the very young – Huib de Jong

Saturday September 8 – 11.50 – Oral communications

Session 7 – Adult height after childhood onset RRT - Jérôme Harambat
Session 9 – Identification of subgroups at high risk of graft failure - Danilo Lofaro

Saturday September 8 – 13.00 – Meeting for registries - Aula Mala meeting room





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, B Pundziene
Austria	R Kramar, R Oberbauer	Malta	V Said-Conti
Belarus	S Baiko, A Sukalo	Montenegro	S Pavićević
Belgium	K van Hoeck, F Collart, JM des Grottes	Norway	T Leivestad, A Bjerre
Bosnia Herzegovina	D Pokrajac	Poland	A Zurowska, I Zagodzdon
Bulgaria	D Roussinov	Portugal	C Mota, M Almeida, C Afonso
Croatia	D Batinić, Maja Lemac, J Slavicek	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, S Puric, D Kruscic, B Spasojevic-Dimitrijeva, G Milosevski-Lomic D Paripovic
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, M Lasalle, J Harambat	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, A Kapogiannis, N Printza C Stefanidis	The Netherlands	S Rossi, E Maurer, B Schnarwyler CE Kuehni, G Laube
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Iceland	R Palsson, V Edvardsson	Ukraine	R Topaloglu, O Soylemezoglu, A Duzova
Israel	Y Frishberg, N Meishish	United Kingdom	D Ivanov
Italy	B Gianoglio, T De Palo, C Pecoraro, S Picca, S Testa, E Vidal, E Verrina		T Feest, C Inward