ESPN/ERA-EDTA Registry

ESPN/ERA-EDTA REGISTRY

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An update on the Registry- October 2017

Jaap Groothoff and Jérôme Harambat

As members of the ESPN/ERA-EDTA Registry committee we would like to thank you again for your participation and efforts to the Registry.

Currently, 37 countries are participating in the Registry, providing information on nearly 20,000 patients who started RRT before the age of 20.

This year the ESPN/ERA-EDTA Registry celebrates its 10th anniversary and we are proud of our achievements. In the past ten years, the Registry published 31 scientific papers in high-ranking medical journals. By 2017, another six papers based on Registry data have been accepted for publication by different journals and some others have been submitted. The full publication list can be found below.

An important part of the Registry's research activities arise from the successful internship programme, which has so far led to 18 fellows from 11 European countries visiting the Registry. In 2017, two fellows joined the Registry. Liz Cuperus, a medical student from Leiden University, the Netherlands, is currently working on a project of transplantation outcomes. Moreover, Michael Böhm from Vienna, Austria recently started a project on the minimum weight at which infants can be transplanted.

If you are also interested in performing a research project on the Registry or would like to know more about participating in the ESPN/ERA-EDTA Registry, please contact Marjolein Bonthuis: m.bonthuis@amc.uva.nl.

We would like to thank you for your fruitful collaboration and hope to work with you in the future to improve 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 nine subsequent years.

In 2015, the overall incidence was 5.8 per million age-related population (pmarp) and ranged from 0.0, as no patients started RRT in that year, to 21.5 pmarp. Prevalence was 33.9 and also showed a wide range from 11.0 to 97.1 pmarp. Five-year survival was 93.4% after start of RRT. Most patients died because of infections.

The country reports provided insights on the performance in each country compared to the average European performance by showing benchmarking figures.

Six papers have been accepted and published in the previous months. The Lancet published our paper on mortality risk disparities showing considerable variation in mortality rates across Europe.

A study on infant dialysis, showing that HD is used in 1 in 8 infants and that clinical outcomes did not differ between infants initiating dialysis on HD or PD, was published in AJKD.

Pediatric Nephrology accepted two papers; an educational review on survival after paediatric RRT, and a paper on prune belly syndrome that demonstrated that RRT outcomes are similar to outcomes of patients receiving RRT for other forms of CAKUT. Furthermore, NDT accepted two Registry papers. The first one on racial variation and cardiovascular risk factors showed that Asian children on RRT had a higher prevalence of those risk factors, which may partially explain the higher mortality risk previously found in this population. The second one was on donor-recipient age combinations and graft survival and showed that kidneys from older donors resulted in good graft outcomes, whereas for young recipients the allocation of kidneys from deceased donors older than 5 years should be prioritized.

These papers would not have been possible without your help and efforts, for which we are very grateful.

Thank you all for making this possible!

Table 1: Incident patients

Incident paediatric patients accepted for renal replacement therapy in 2015 and general population characteristics of countries contributing 2015 data to the ESPN/ERA-EDTA Registry.

Country	Total RRT patients 0-14 years		General Population Characteristics		
			Children 0-14 years	Total Population 0-99 years	Children 0-14 years
	N	pmarp	N	N	percent
Albania	5	9.1	546,473	2,894,476	18.9
Austria	5	4.1	1,226,013	8,584,926	14.3
Belarus	6	3.9	1,549,332	9,498,364	16.3
Bosnia and Herzegovina	2	3.7	543,719	3,531,159	15.4
Bulgaria	9	9.0	998,201	7,177,992	13.9
Croatia	3	4.9	616,262	4,207,993	14.6
Cyprus	3	21.5	139,372	847,665	16.4
Czech Republic	8	5.0	1,612,381	10,546,060	15.3
Denmark	4	4.2	961,460	5,683,484	16.9
Estonia	2	9.5	210,551	1,315,407	16.0
Finland	13	14.5	896,315	5,479,531	16.4
France	83	6.7	12,343,340	66,624,068	18.5
FYR of Macedonia	1	2.9	346,278	2,069,933	16.7
Georgia	5	6.6	760,455	4,483,230	17.0
Germany-KFH*	30	2.8	10,783,924	81,686,609	13.2
Germany-CERTAIN*	2	0.2	10,783,924	81,686,609	13.2
Greece	9	5.7	1,567,341	10,820,884	14.5
Hungary	19	13.3	1,425,817	9,843,026	14.5
Iceland	0	0.0	66,771	330,815	20.2
Italy*	28	3.4	8,332,490	60,730,580	13.7
Latvia	1	3.3	298,990	1,977,530	15.1
Lithuania	4	9.4	424,604	2,904,908	14.6
Malta	0	0.0	61,669	431,872	14.3
Norway	10	10.7	933,068	5,188,609	18.0
Poland	23	4.0	5,711,822	37,986,409	15.0
Portugal	10	6.8	1,475,536	10,358,076	14.2
Republic of Serbia	5	4.9	1,022,023	7,095,382	14.4
Romania	10	3.3	3,073,038	19,815,478	15.5
Russia	71	3.3	21,534,456	142,368,368	15.1
Slovakia	3	3.6	831,113	5,423,799	15.3
Slovenia	0	0.0	305,351	2,063,532	14.8
Spain	42	6.0	7,037,240	46,447,697	15.2
Sweden	9	5.3	1,699,588	9,799,186	17.3
Switzerland	12	9.7	1,236,729	8,237,126	15.0
the Netherlands	20	7.1	2,813,419	16,939,923	16.6
Turkey*	51	2.7	18,874,324	78,218,476	24.1
Ukraine	19	2.9	6,494,293	42,590,879	15.9
United Kingdom	115	10.0	11,530,789	65,110,034	17.7
Total*	**531**	**5.8**	**92,293872**	**578,677,821**	**15.9**

* The incidence of German dialysis patients (KfH) is an underestimation of the true incidence since data from one centre are not included. In 2015, 119 patients under the age of 21 years were transplanted in Germany. In Italy, (pre-emptive) transplantation patients are not included; these numbers are an underestimation of true incidence. The incidence in Turkey is an underestimation of the true incidence. Therefore, Germany, Italy, and Turkey were excluded from the overall incidence.

Table 2: Treatment modality at start of RRT in 2015

Treatment modality at day 1, among patients < 15 years of age starting RRT in 2015.
Patients from Germany, Italy, and Turkey are excluded.

	N	Percent	Pmarp
HD at start	226	42.6	2.45
PD at start	207	39.0	2.24
Pre-emptive transplantation	97	18.3	1.05
Unknown	1	0.1	0.01

Table 3: PRD distribution at start of RRT in 2015

Cause of renal failure, among patients < 15 years of age, starting RRT in 2015 according to new and old PRD coding.

	N		Percent		Pmarp	
	New	Old	New	Old	New	Old
CAKUT	198	170	37.3	32.0	2.19	1.84
Glomerulonephritis	96	82	18.1	15.4	1.08	0.89
Cystic kidney disease	60	65	11.2	12.2	0.70	0.70
Hereditary nephropathy	-	25	-	4.7	-	0.27
Metabolic and tubulointerstitial disorders	20	7	3.8	1.3	0.21	0.08
Toxic/ischemic renal failure	12	8	2.3	1.5	0.14	0.09
HUS	18	15	3.4	2.8	0.20	0.16
Vascular	5	4	0.9	0.8	0.06	0.04
Miscellaneous	70	75	13.2	14.1	0.78	0.81
Unknown	52	80	9.8	15.1	0.61	0.87

Table 4: eGFR at start of RRT

Estimated GFR based on age, height and serum creatinine levels, calculated according to the new bedside Schwartz formula, among incident patients, age <15 years in 2015.

	N	Percent
eGFR<8 ml min^{-1} per 1.73 m^2	137	39.8
eGFR 8- 15 ml min^{-1} per 1.73 m^2	162	47.1
eGFR>15 ml min^{-1} per 1.73 m^2	45	13.1

Table 5: Prevalent Patients

Prevalent paediatric patients on renal replacement therapy on the 31st of December 2015. Prevalent counts and prevalence per million age related population, by age groups.

Country	Total RRT		Age Groups		
	0-14 years		Infants 0-4 years	Children 5-9 years	Adolescents 10-14 years
	N	pmarp	pmarp	pmarp	pmarp
Albania	6	11.0	0.0	12.1	19.2
Austria	50	40.8	17.2	52.0	52.9
Belarus	38	24.5	6.8	24.9	47.5
Bosnia and Herzegovina	12	22.1	40.2	5.7	20.8
Bulgaria	18	18.0	3.0	11.6	41.0
Croatia	25	40.6	19.8	37.9	63.9
Cyprus	9	64.6	83.9	85.2	22.3
Czech Republic	46	28.5	12.6	18.9	58.9
Denmark	35	36.4	16.9	36.2	54.0
Estonia	4	19.0	0.0	0.0	63.0
Finland	87	97.1	80.7	71.9	139.9
France	477	38.6	19.1	32.0	64.0
FYR of Macedonia	5	14.4	0.0	35.2	8.5
Georgia	13	17.1	7.1	17.3	28.1
Germany-KFH*	128	11.9	13.0	10.2	12.4
Germany-CERTAIN*	218	20.2	5.6	22.1	32.4
Greece	57	36.4	8.2	41.9	56.7
Hungary	53	37.2	8.8	30.5	70.7
Iceland	4	59.9	0.0	43.1	140.8
Italy*	260	31.2	14.9	30.4	46.9
Latvia	5	16.7	9.8	9.6	32.5
Lithuania	8	18.8	13.2	21.5	22.3
Malta	2	32.4	0.0	49.3	49.6
Norway	53	56.8	35.8	40.8	94.3
Poland	221	38.7	17.3	34.1	66.7
Portugal	80	54.2	18.1	46.3	91.6
Republic of Serbia	32	31.3	9.1	29.7	53.2
Romania	42	13.7	4.2	13.1	22.8
Russia	396	18.4	8.4	16.9	32.0
Slovakia	18	21.7	17.4	17.8	30.4
Slovenia	6	19.6	36.9	19.0	0.0
Spain	291	41.4	16.1	43.9	62.7
Sweden	93	54.7	25.6	55.1	86.1
Switzerland	52	42.0	23.6	21.8	82.4
the Netherlands	125	44.4	19.3	55.9	55.9
Turkey*	269	14.3	6.0	11.1	25.9
Ukraine	78	11.9	2.2	12.6	23.2
United Kingdom	687	59.6	29.5	62.2	90.7
Total*	**3128**	**33.9**	**15.5**	**32.4**	**55.1**

* The prevalence of German dialysis patients (KfH) is an underestimation of the true prevalence since data from one centre are not included. In 2015, 119 patients under the age of 21 years were transplanted in Germany. In Italy, (pre-emptive) transplantation patients are not included; these numbers are an underestimation of true prevalence. The prevalence in Turkey is an underestimation of the true prevalence. Therefore, Germany, Italy, and Turkey were excluded from the overall prevalence.

Table 5: Prevalent Patients (continued)

Prevalent paediatric patients on renal replacement therapy on the 31st of December 2015. Prevalent counts and prevalence per million age related population, by age groups.

Country	Gender		Treatment modality		
	Male 0-14 years pmarp	Female 0-14 years pmarp	HD 0-14 years pmarp	PD 0-14 years pmarp	Transplantation 10-14 years pmarp
Albania	7.0	15.3	5.5	0.0	5.5
Austria	49.3	31.8	3.3	1.6	35.9
Belarus	32.6	16.0	2.6	4.5	17.4
Bosnia and Herzegovina	28.7	15.1	12.9	3.7	5.5
Bulgaria	21.4	14.4	6.0	2.0	8.0
Croatia	44.2	36.8	9.7	27.6	3.2
Cyprus	55.9	73.7	7.2	28.7	28.7
Czech Republic	36.3	20.4	3.7	5.6	19.2
Denmark	48.7	23.5	2.1	2.1	31.2
Estonia	18.5	19.5	4.7	0.0	14.2
Finland	106.9	86.7	5.6	8.9	82.6
France	44.8	32.2	6.9	3.7	28.0
FYR of Macedonia	16.8	12.0	5.8	5.8	2.9
Georgia	20.0	13.9	6.6	6.6	3.9
Germany-KFH*	13.7	9.9	3.9	7.8	-
Germany-CERTAIN*	23.8	16.4	-	-	20.2
Greece	42.3	28.8	8.9	12.8	14.7
Hungary	43.7	30.3	4.9	4.2	28.1
Iceland	88.0	30.6	0.0	0.0	59.9
Italy*	36.9	25.2	5.3	8.9	-
Latvia	19.5	13.8	0.0	3.3	13.4
Lithuania	13.8	24.1	0.0	14.1	4.7
Malta	31.4	33.5	0.0	0.0	32.4
Norway	67.0	46.1	1.1	3.2	52.5
Poland	46.7	30.2	3.5	7.5	27.7
Portugal	60.9	47.2	3.4	11.5	39.3
Republic of Serbia	28.5	34.3	5.9	3.9	20.5
Romania	13.9	13.4	8.8	4.2	0.7
Russia	22.3	14.3	3.4	6.5	8.5
Slovakia	21.1	22.2	6.0	9.6	6.0
Slovenia	31.8	6.7	0.0	6.5	13.1
Spain	50.5	31.7	4.0	2.3	35.1
Sweden	67.5	41.1	2.4	2.9	48.8
Switzerland	34.9	48.8	1.6	5.7	34.8
the Netherlands	53.5	34.9	3.6	2.8	38.0
Turkey*	15.4	13.1	2.8	5.8	5.6
Ukraine	12.9	11.1	3.5	2.5	6.0
United Kingdom	75.7	42.7	8.1	7.2	44.1
Total*	**40.6**	**26.7**	**4.9**	**5.5**	**23.4**

* The prevalence of German dialysis patients (KfH) is an underestimation of the true prevalence since data from one centre are not included. In 2015, 119 patients under the age of 21 years were transplanted in Germany. In Italy, (pre-emptive) transplantation patients are not included; these numbers are an underestimation of true prevalence. The prevalence in Turkey is an underestimation of the true prevalence. Therefore, Germany, Italy, and Turkey were excluded from the overall prevalence.

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	47.5 (45.7-49.3)	28.8 (27.6-30.0)
Mean z-score systolic blood pressure	1.32 (1.26-1.37)	0.84 (0.80-0.87)
Mean z-score diastolic blood pressure	1.17 (1.13-1.22)	0.66 (0.63-0.69)
Height		
% of patients with height z-score < -2	52.4 (51.0-53.7)	40.8 (39.5-42.0)
Mean height z-score	-2.09 (-2.15; -2.02)	-1.82 (-1.86; -1.78)

Figure 1: Five-year survival

Incident RRT patients under the age of 15 starting RRT from 2007 onwards. Follow-up till 31st of December 2015.

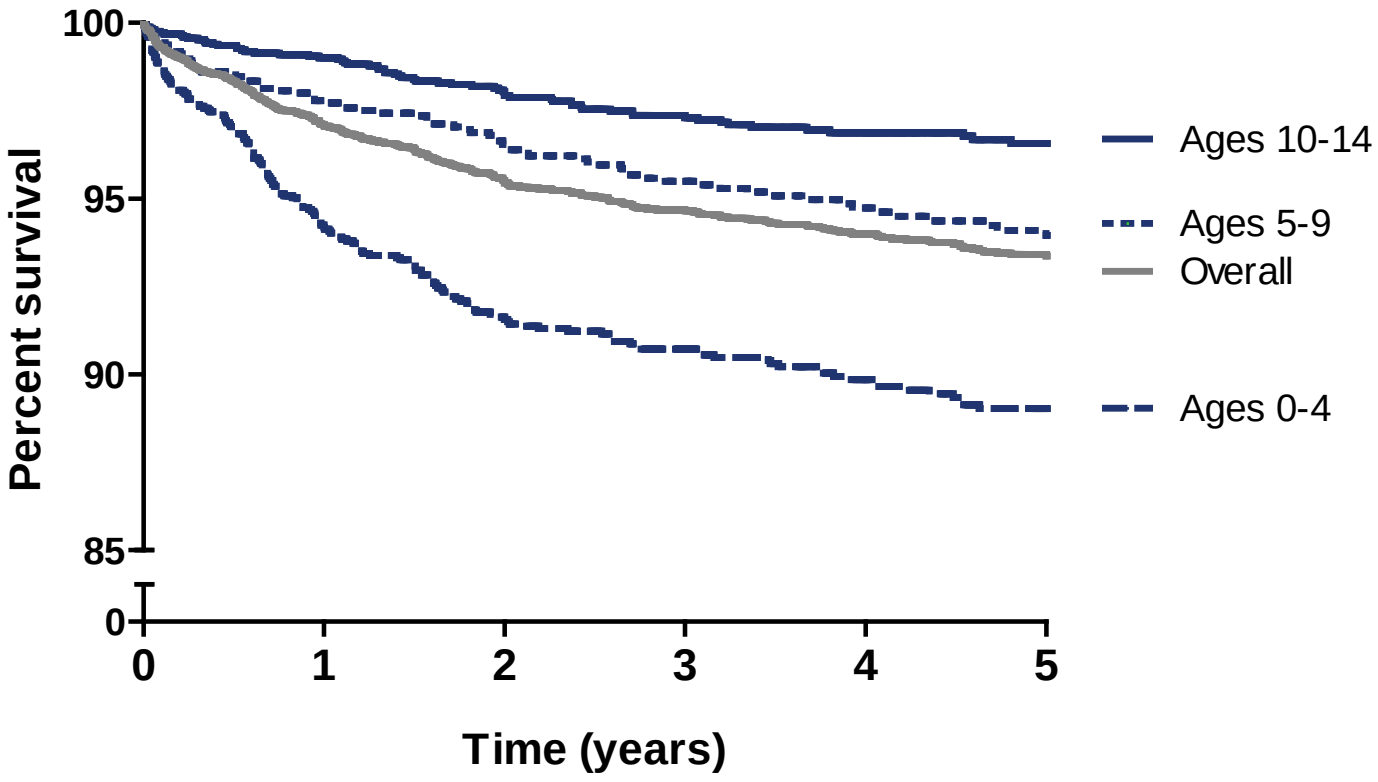

Table 7: Causes of Death

Causes of death according to the ERA-EDTA coding lists. Incident RRT patients under the age of 15 starting RRT from 2007 onwards. Follow-up till 31st of December 2015.

Cause of death	Number of deaths	Percent
Myocardial ischemia and infarction	3	0.8
Cardiac failure	34	8.6
Cardiac arrest/sudden death other cause	45	11.4
Cerebro-vascular accident	27	6.8
Infection	83	21.0
Suicide /refusal or cessation of treatment	5	1.3
Treatment withdrawn	7	1.8
Malignant disease	12	3.0
Other identified cause of death	69	17.4
Cause of death uncertain/not determined	111	28.0

ESPN/ERA-EDTA Registry Scientific Committee

ESPN/ERA-EDTA Registry

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Publication list 2017

1. Infants requiring maintenance dialysis: outcomes of hemodialysis and peritoneal dialysis. Vidal E, van Stralen KJ, Chesnaye NC, Bonthuis M, Holmberg C, Zurowska A, Trivelli A, Eduardo Esteves Da Silva J, Herthelius M, Adams B, Bjerre A, Jankauskiene A, Miteva P, Emirova K, Bayazit AK, Mache JC, Sánchez-Moreno A, Harambat J, Groothoff JW, Jager KJ, Schaefer F, Verrina E. *Am J Kidney Dis. 2017 May;69(5):617-625.*

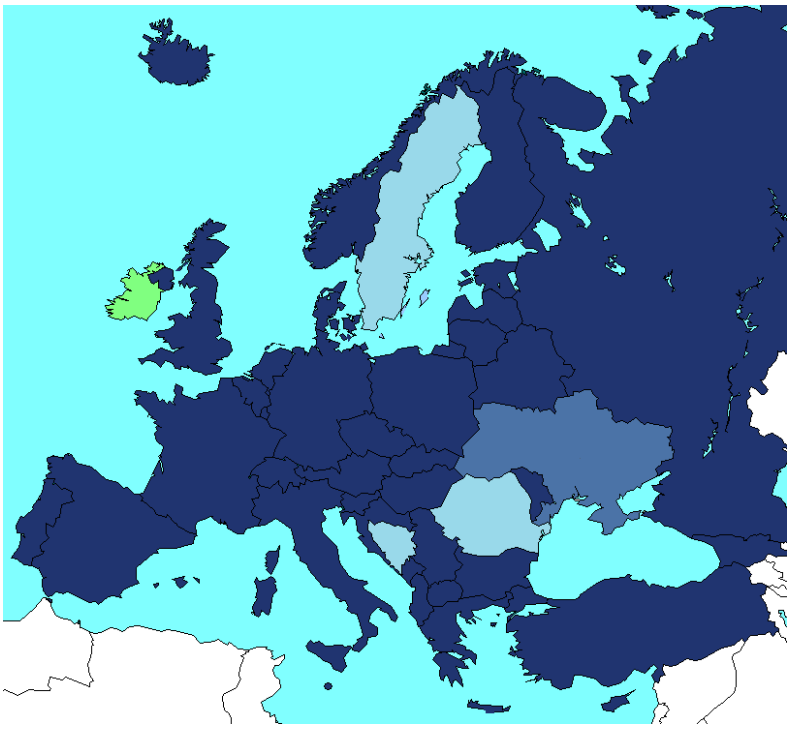
2. Mortality risk disparities in children receiving chronic renal replacement therapy for the treatment of end-stage renal disease across Europe. An ESPN/ERA-EDTA Registry analysis. Chesnaye NC, Schaefer F, Bonthuis M, Holman R, Baiko S, Baskin E, Bjerre A, Cloarec S, Cornelissen EAM, Espinosa L, Heaf JG, Stone R, Shtiza D, Zagozdzon I, Harambat J, Jager KJ, Groothoff JW, van Stralen KJ. *Lancet. 2017 May;389(10084):2128-2137.*

3. Racial variation in cardiovascular disease risk factors among European children on renal replacement therapy- Results from the ESPN/ERA-EDTA Registry. Tjaden LA, Jager KJ, Bonthuis M, Kuehni C, Lilien MR, Seeman T, Stefanidis CJ, Tse Y, Harambat J, Groothoff JW, Noordzij M. *Nephrol Dial Transplant 2017 [Epub ahead of print].*

4. Survival in children requiring chronic renal replacement therapy. Chesnaye NC, van Stralen KJ, Bonthuis M, Harambat J, Groothoff JW, Jager KJ. *Pediatr Nephrol. 2017 [Epub ahead of print].*

5. Outcomes of renal replacement therapy in boys with prune belly syndrome: findings from the ESPN/ERA-EDTA Registry. Yalcinkaya, F, Bonthuis M, Doganay Erdogan B, van Stralen KJ, Baiko S, Chehade H, Maxwell H, Montini G, Rönnholm K, Schwartz Sørenson S, Ulinski T, Verrina E, Weber S, Harambat J, Schaefer F, Jager KJ, Groothoff JW. *Pediatr Nephrol 2017 [Epub ahead of print].*

6. The association of donor and recipient age with graft survival in pediatric renal transplant recipients an ESPN/ERA-EDTA Registry study. Chesnaye NC, van Stralen KJ, Bonthuis M, Groothoff JW, Harambat J Schaefer F, Canpolat N, Garnier A, Heaf J, de Jong H, Schwartz Sørenson S, Tönshoff B, Jager KJ. *Nephrol Dial Transplant 2017 [Epub ahead of print].*



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 to the Registry

Albania	D Shtiza
Austria	R Kramar
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Belgium	K van Hoeck and the Centre contributors to the Belgian Registry Committee
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Bulgaria	D Roussinov
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Cyprus	A Elia
Czech Republic	T Seeman, K Vondrak
Denmark	JG Heaf
Estonia	Ü Toots
Finland	P Finne, A Pylsy, P-H Groop
France	C Couchoud, M Lassalle, E Berard
FYR of Macedonia	E Sahpazova, N Abazi
Georgia	T Davitaia
Germany - CERTAIN	K Krupka, B Höcker, L Pape, B Tönshoff
Germany - KfH	K Rascher, E Nüsken, L Weber, G von Gersdorff, Prof. Jörg Dötsch, F Schaefer
Greece	N Afentakis, A Kapogiannis, N Printza, C Stefanidis
Hungary	G Reusz, Cs Berecki, A Szabó, T Szabó, A Barczi, O Lakatos, E Kis
Iceland	R Palsson, V Edvardsson
Italy	B Gianoglio, I Guzzo, B Minale, R Roperto, S Testa, E Vidal, E Verrina
Latvia	H Čerņevskis, V Kuzema
Lithuania	S Rudaitis, A Jankauskiene
Malta	V Said-Conti
Moldova	S Gatcan, O Berbeca, N Zaikova, N Revenco
Montenegro	S Pavićević
Norway	A Åsberg, AV Reisæter, A Bjerre
Poland	A Zurowska, I Zagozdzon
Portugal	C Mota, R Stone, C Afonso
Romania	G Mircescu, L Garneata
Russia	EA Molchanova, NA Tomilina
Serbia	M Kostić, B Spasojević, M Cvetković, I Gojković, D Paripović, G Miloševski-Lomić
Slovakia	L Podracka, G Kolvek
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