

An update on the Registry- October 2014



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As members of the ESPN/ERA-EDTA Registry committee we want to thank you again for your great participation and enthusiasm for the Registry. Currently, 35 countries are participating in the registry, providing information on more than 10,000 patients who started RRT before the age of 20, between 1997 and 2012. But there is more! In 2014, three pa-

pers based on Registry data have been accepted for publication at different journals and several others have been submitted.

As you may have heard, after seven years of working for the Registry, Karlijn van Stralen decided to accept a position outside our Registry. Marjolein Bonthuis, who used to be a PhD student on the registry, has replaced her as of the first of September. In order to ensure a smooth transition, Karlijn van Stralen will stay involved in the Registry as an advisor.

Also this year, many visiting researchers came to the AMC. In April, Beyza Erdogan from Turkey visited the Registry for a study on Prune Belly syndrome. Furthermore, Julian Hogan

from France studied gender differences on the transplant waiting list and found that females were less likely to receive a renal transplant. Three other internships have been approved. Many interesting studies are therefore coming up!

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 contact Marjolein Bonthuis: m.bonhuis@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 seven subsequent years. In 2012, the overall incidence was 3.9 per million age-related population (pmarp) and ranged from 0, as no patients started RRT in that year, to 13.1 pmarp. The prevalence also shows a wide range from 1.7 to 120.5 pmarp. Five-year survival was 93.8% after start of RRT. The most important cause of death was infection related.

As last year, the 2012 country reports contained important benchmarking figures for several clinical parameters. In this way, the patient performance on these clinical parameters in each coun-

try could be compared to the performance of all patients in Europe. Moreover, this year some countries reported primary renal diseases according to the new ERA-EDTA coding system. As this provides more detailed information on the diagnosis of renal disease, the new coding system will be used in the future.

Furthermore, three papers have been accepted and published in the previous months. Two papers have been accepted by *Pediatric Nephrology*. One on the likelihood to live with a functioning transplant¹, and one showing demographic data on European paediatric RRT patients for the years 2009-2011². The former project showed that the variation in paediatric

kidney transplantation across Europe is mainly explained by macroeconomic indicators, like GDP. Moreover, the collaborative project between the ESPN/ERA-EDTA, IPPN, Japanese and ANZDATA registries on starting dialysis in the neonatal period has been published by *Kidney International*³. This study showed that patient survival was relatively good at the median-run, but growth retardation, anaemia, and hypertension were very frequent in this challenging patient population.

These papers would not have been possible without your help, 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 2012 and general population characteristics of countries contributing 2012 data to the ESPN/ERA-EDTA registry.

Country	Total		General Population Characteristics		
	RRT patients		Children	Total Population	Children
	0-14 years		0-14 years	0-99 years	0-14 years
	N	pmarp	N	N	percent
Albania	2	3.5	569,116	2,801,681	20.3
Austria	5	4.1	1,224,361	8,443,018	14.5
Belarus	6	4.1	1,460,265	9,463,840	15.4
Bosnia and Herzegovina	2	3.3	607,160	3,507,928	17.3
Bulgaria	5	5.1	984,972	7,305,888	13.5
Croatia	5	7.8	640,854	4,269,063	15.0
Czech Republic	4	2.6	1,550,769	10,510,787	14.8
Denmark	7	7.0	994,371	5,648,410	17.6
Estonia	0	0.0	208,330	1,329,299	15.7
Finland	7	7.9	890,187	5,413,969	16.4
France	55	4.5	12,145,883	65,442,570	18.6
FYR of Macedonia	0	0.0	352,439	2,060,630	17.1
Germany*	10	1.2	10,784,544	81,932,163	13.2
Greece	11	6.8	1,625,871	11,092,771	14.7
Hungary	9	6.3	1,435,577	9,920,363	14.5
Iceland	0	0.0	66,375	320,717	20.7
Italy*	31	3.7	8,336,778	59,539,718	14.0
Lithuania	2	4.5	440,318	2,987,774	14.7
Malta	0	0.0	61,489	419,455	14.7
Moldova	1	1.7	575,039	3,559,518	16.2
Norway	5	5.4	925,479	5,018,571	18.4
Poland	25	4.3	5,807,795	38,535,872	15.1
Portugal	16	10.2	1,561,550	10,514,841	14.9
Romania	15	4.7	3,189,646	20,121,641	15.9
Russia	83	3.9	21,534,456	142,368,368	15.1
Serbia	3	2.9	1,033,872	7,199,078	14.4
Slovakia	1	1.2	831,574	5,407,578	15.4
Slovenia	1	3.4	296,122	2,057,157	14.4
Spain	29	4.1	7,083,469	46,773,060	15.1
Sweden	21	13.1	1,598,064	9,519,374	16.8
Switzerland	14	11.7	1,200,603	8,039,060	14.9
the Netherlands	18	6.2	2,887,290	16,754,964	17.2
Turkey*	46	2.4	18,871,877	75,175,825	25.1
United Kingdom	97	8.7	11,213,764	63,705,030	17.6
Total*	480	3.9	93,333,838	590,051,993	15.8

* Data from Germany are only based on transplantation patients from 16 out of 20 transplantation centers, dialysis patients are not included and are therefore an underestimation of the true incidence. Each year, around 120 patients are transplanted, of which 16% pre-emptively. The incidence for Turkey is an underestimation of the true incidence. Therefore, Germany and Turkey were excluded from the overall incidence. In Italy, (pre-emptive) transplantation patients are not included; these numbers are an underestimation of true incidence.

Table 2: Treatment modality at start of RRT in 2012

Treatment modality at day 1, among patients < 15 years of age starting RRT in 2012. Patients with a pre-emptive transplantation from Italy were excluded, as were dialysis patients from Germany, and all Turkish patients.

	N	Percent	Pmarp
HD at start	180	37.5	1.60
PD at start	185	38.5	1.65
Pre-emptive transplantation	86	17.9	0.76
Unknown	29	6.0	0.24

Table 3: PRD distribution at start of RRT in 2012

Cause of renal failure, among patients < 15 years of age, starting RRT in 2012 according to new and old PRD coding

	N		Percent		Pmarp	
	New	Old	New	Old	New	Old
CAKUT	161	162	30.0	30.2	1.31	1.34
Glomerulonephritis	79	75	14.7	14.0	0.64	0.62
Cystic kidney disease	62	62	11.6	11.6	0.51	0.51
Hereditary nephropathy	-	31	-	5.8	-	0.26
Metabolic and tubulointerstitial disorders	18	13	3.4	2.5	0.15	0.11
Toxic/ischemic renal failure	8	4	1.5	0.7	0.07	0.03
HUS	16	16	3.0	3.0	0.13	0.13
Vascular	4	4	0.7	0.7	0.03	0.03
Pyelonephritis	-	14	-	2.6	-	0.12
Miscellaneous	113	40	21.1	7.5	0.92	0.33
Unknown	47	115	7.9	21.5	0.36	0.95

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 2012

	N	percent
eGFR<8 ml min⁻¹ per 1.73 m²	95	42.4
eGFR 8- 15 ml min⁻¹ per 1.73 m²	112	50.0
eGFR>15 ml min⁻¹ per 1.73 m²	17	7.6

Table 5: Prevalent Patients

Prevalent paediatric patients on renal replacement therapy on the 31st of December 2012. Prevalent counts and prevalence per million age related population, by age groups.

Country	Total		Age Groups		
	RRT patients		Infants	Children	Adolescents
	0-14 years		0-4 years	5-9 years	10-14 years
	N	pmarp	pmarp	pmarp	pmarp
Albania	5	8.8	0.0	5.6	17.6
Austria	47	38.4	17.8	39.4	56.6
Belarus	30	20.5	9.1	17.4	37.7
Bosnia and Herzegovina	10	16.5	37.3	0.0	17.8
Bulgaria	12	12.2	0.0	0.0	38.2
Croatia	26	40.6	37.6	24.4	58.3
Czech Republic	35	22.6	1.7	43.1	26.4
Denmark	53	53.3	28.1	36.0	93.8
Estonia	2	9.6	0.0	14.3	16.5
Finland	75	84.3	56.0	91.5	106.3
France	414	34.1	13.2	34.3	54.6
FYR of Macedonia	5	14.2	0.0	26.5	16.2
Germany*	185	21.6	7.8	27.6	28.3
Greece	57	35.1	19.9	28.0	57.8
Hungary	43	30.0	10.7	31.0	47.5
Iceland	8	120.5	85.2	92.6	187.8
Italy*	262	31.4	16.8	30.7	46.5
Lithuania	9	20.4	6.7	22.2	32.2
Malta	4	65.1	0.0	51.5	138.2
Moldova	1	1.7	0.0	0.0	5.1
Norway	44	47.5	19.2	56.0	67.7
Poland	237	40.8	19.9	39.6	64.7
Portugal	84	53.8	20.6	57.8	78.9
Romania	46	14.4	7.7	10.4	24.8
Russia	322	15.0	6.7	13.6	26.4
Serbia	31	30.0	9.0	28.5	51.4
Slovakia	19	22.8	3.4	15.0	51.1
Slovenia	12	40.5	9.1	21.3	97.8
Spain	279	39.4	16.7	42.6	61.0
Sweden	90	56.3	31.6	57.7	83.7
Switzerland	58	48.3	9.9	53.8	81.3
the Netherlands	133	46.1	24.0	43.8	68.1
Turkey*	328	17.4	7.7	11.8	31.8
United Kingdom	585	52.2	24.5	51.4	83.9
Total*	3038	32.6	14.7	32.0	52.2

* Data from Germany are only based on transplantation patients from 16 out of 20 transplantation centers, dialysis patients are not included and are therefore an underestimation of the true prevalence. Each year, around 120 patients are transplanted, of which 16% pre-emptively. The prevalence for Turkey is an underestimation of the true prevalence. Therefore, Germany and Turkey were excluded from the overall prevalence. In Italy, (pre-emptive) transplantation patients are not included; these numbers are an underestimation of true prevalence.

Table 5: Prevalent Patients (continued)

Prevalent paediatric patients on renal replacement therapy on the 31st of December 2012. 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 pmarp	0-14 years pmarp	0-14 years pmarp	0-14 years pmarp	0-14 years pmarp
Albania	13.5	3.7	8.8	0.0	0.0
Austria	54.2	21.8	1.6	3.3	33.5
Belarus	18.6	22.6	2.7	4.8	13.0
Bosnia and Herzegovina	16.1	16.8	11.5	0.0	4.9
Bulgaria	17.8	6.3	7.1	2.0	3.0
Croatia	42.6	38.5	1.6	20.3	18.7
Czech republic	28.9	15.9	1.9	5.2	15.5
Denmark	70.7	35.0	5.0	5.0	42.2
Estonia	9.3	9.9	0.0	0.0	9.6
Finland	90.1	78.1	3.4	7.9	73.0
France	39.9	28.0	5.2	2.8	25.8
FYR of Macedonia	11.0	17.6	2.8	8.5	2.8
Germany*	25.5	17.5			16.2
Greece	39.7	30.2	6.8	11.1	16.6
Hungary	33.9	25.8	2.1	8.4	19.5
Iceland	118.0	123.1	15.1	30.1	75.3
Italy*	36.4	26.1	4.7	9.4	
Lithuania	13.3	28.0	4.5	6.8	9.1
Malta	63.4	66.8	0.0	0.0	65.1
Moldova	3.4	0.0	0.0	1.7	0.0
Norway	54.9	39.9	4.3	1.1	42.1
Poland	47.6	33.6	3.4	7.4	29.1
Portugal	67.6	39.3	4.5	15.4	33.3
Romania	15.3	13.5	5.0	6.9	2.5
Russia	16.8	13.0	2.7	5.0	7.1
Serbia	30.1	29.9	5.8	1.9	22.2
Slovakia	28.1	17.3	2.4	13.2	6.0
Slovenia	52.5	27.8	6.8	6.8	27.0
Spain	46.6	31.7	3.8	4.0	31.6
Sweden	68.2	43.7	3.8	6.3	46.3
Switzerland	55.1	41.1	4.2	4.2	35.8
the Netherlands	58.2	33.3	2.4	3.8	39.8
Turkey*	19.3	15.4			
United Kingdom	62.4	41.5	5.2	4.9	40.7
Total*	38.2	26.6	4.0	5.5	22.8

* Data from Germany are only based on transplantation patients from 16 out of 20 transplantation centers, dialysis patients are not included and are therefore an underestimation of the true prevalence. Each year, around 120 patients are transplanted, of which 16% pre-emptively. The prevalence for Turkey is an underestimation of the true prevalence. Therefore, Germany and Turkey were excluded from the overall prevalence. In Italy, (pre-emptive) transplantation patients are not included; these numbers are an underestimation of true prevalence.

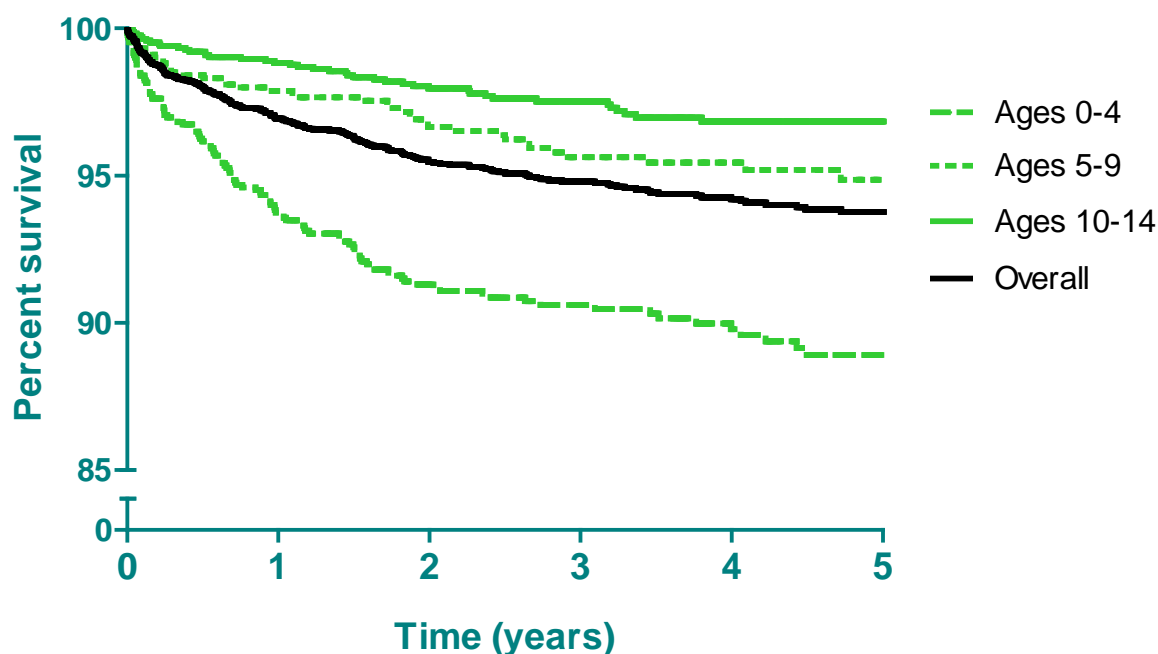
Table 6: Hypertension and height in children on RRT

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	47.3 (45.1 - 49.4)	27.2 (25.7 - 28.7)
Mean z-score systolic blood pressure	1.31 (1.25 - 1.39)	0.81 (0.77 - 0.86)
Mean z-score diastolic blood pressure	1.16 (1.10 - 1.23)	0.62 (0.59 - 0.66)
Height		
% of patients with height z-score < -2	52.4 (50.6 - 54.2)	42.0 (40.4 - 43.5)
Mean height z-score	-2.14 (-2.22 ; -2.05)	-1.81 (-1.87 ; -1.76)

Figure 1: Two-year survival

Incident RRT patients under the age of 15 starting RRT from 2007 onwards. Follow-up till 31st of December 2012.



Data included:

Austria, Belarus, Bosnia and Herzegovina, Bulgaria, Croatia, Czech republic, Denmark, Estonia, Finland, France, FYR of Macedonia, Germany, Greece, Hungary, Iceland, Italy, Lithuania, Malta, Moldova, Norway, Poland, Portugal, Romania, Russia, Serbia, Slovenia, Slovakia, Spain, Sweden, Switzerland, the Netherlands, Turkey, 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 from 2007 onwards. Follow-up till 31st of December 2012.

	Number of deaths	Percent
Cardiac failure	13	6.0
Myocardial ischemia and infarction	1	0.5
Cardiac arrest/sudden death other cause	18	8.3
Cerebro-vascular accident	15	6.9
Infection	41	18.9
Suicide /refusal or cessation of treatment	3	1.4
Malignant disease	8	3.7
Treatment withdrawn	5	2.3
Other identified cause of death	43	19.7
Cause of death uncertain/not determined	70	32.3

ESPN/ERA-EDTA Registry

Scientific Committee

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Publication list ESPN/ERA-EDTA registry 2014

1. Likelihood of children with end-stage kidney disease in Europe to live with a functioning kidney transplant is mainly explained by non-medical factors.

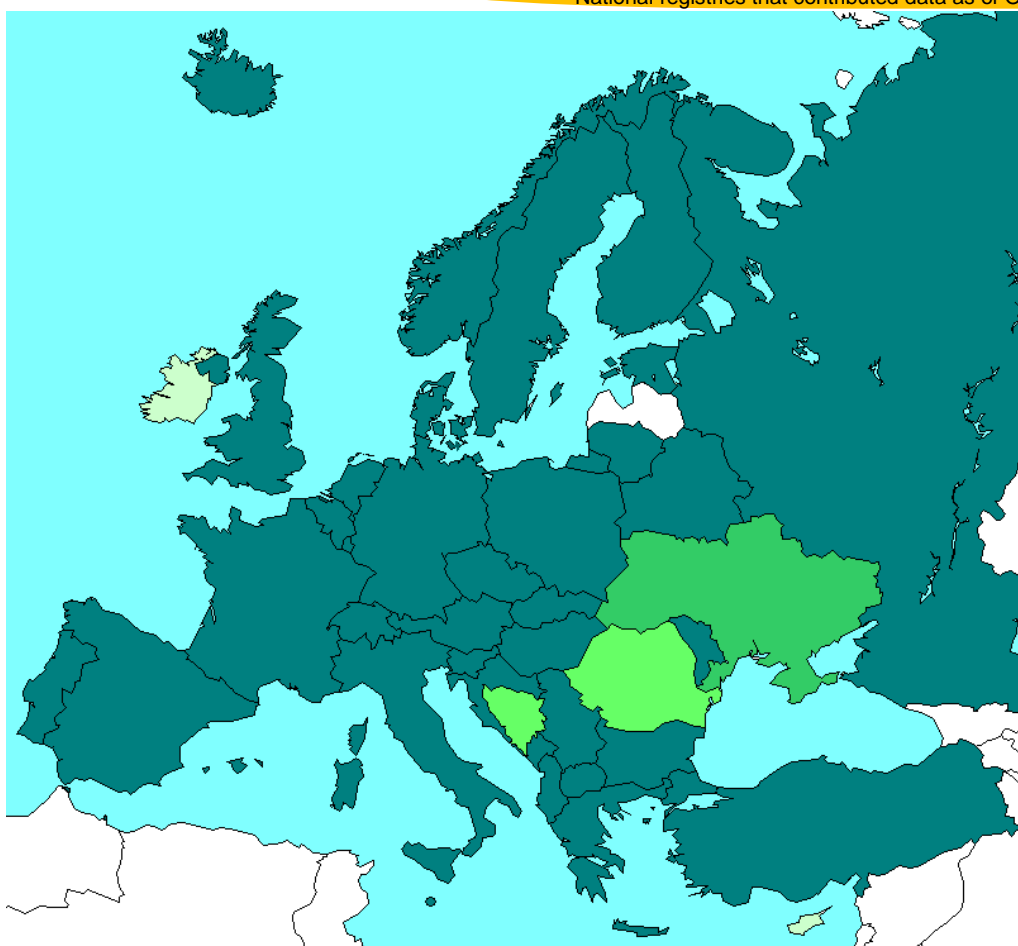
Harambat J, van Stralen KJ, Verrina E, Groothoff JW, Schaefer F, Jager KJ. Pediatr Nephrol 2014 Mar 29(3): 453-9.

2. Demographics of paediatric renal replacement therapy in Europe: a report of the ESPN/ERA-EDTA registry.

Chesnaye N, Bonthuis M, Schaefer F, Groothoff JW, Verrina E, Heaf JG, Jankauskiene A, Lukosiene V, Molchanova EA, Mota C, Peco-Antić A, Ratsch IM, Bjerre A, Roussinov DL, Sukalo A, Topaloglu R, Van Hoeck K, Zagozdzon I, Jager KJ, Van Stralen KJ; Pediatr Nephrol 2014 (ahead of print)

3. Survival and clinical outcomes of children starting renal replacement therapy in the neonatal period.

van Stralen KJ, Borzych-Dużalka D, Hataya H, Kennedy SE, Jager KJ, Verrina E, Inward C, Rönnholm K, Vondrak K, Warady BA, Zurowska AM, Schaefer F, Cochat P; ESPN/ERA-EDTA registry; IPPN registry; ANZDATA registry; Japanese RRT registry; Kidney Int 2014 Jul; 86(1): 168-74.



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 Shtiza	Malta	V Said-Conti
Austria	R Kramar, R Oberbauer	Moldova	S Gatcan, O Berbeca, N Zaikova
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 Zagodzdn
Bulgaria	D Roussinov	Portugal	C Mota, M Almeida, C Afonso
Croatia	D Batinić, M Lemac, J Slavicek	Romania	G Mircescu, L Garneata
Czech Republic	T Seeman, K Vondrak	Russia	EA Molchanova, NA Tomilina, BT Bikbov
Denmark	JG Heaf	Serbia	M Kostic, A Peco-Antic, S Spasojevic- Dimitrijeva, G Milosevski-Lomic, D Paripovic, S Puric, D Kruscic
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, N Abazi, N Ristoka Bojkovska	Sweden	S Schön, KG Prütz, L Bäckman, M Evans, M Stendahl, B Rippe
Germany	F Schaefer, G Gernsdorf, C Barth, C Scholz, B Tönshoff, K Krupka, B Höcker, L Pape	Switzerland	E Maurer, G Laube, CE Kuehni, H Chehade, C Rudin
Greece	N Afentakis, A Kapogiannis, N Printza, C Stefanidis	The Netherlands	A Hoitsma, A Hemke, and all centres participating in the RICHQ-study
Hungary	G Reusz, Cs Berecki, A Szabó, T Szabó, Zs Györke, E Kis	Turkey	R Topaloglu, A Duzova
Iceland	R Palsson, V Edvardsson	Ukraine	D Ivanov
Italy	B Gianoglio, S Maringhini, C Pecoraro, S Picca, S Testa, E Vidal, E Verrina	United Kingdom	R Pruthi, F Braddon, S Mannings, A Causula, MD Sinha
Lithuania	A Jankauskiene, B Pundziene		