

## An update on the Registry- September 2015



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**A**s members of the ESPN/ERA-EDTA Registry committee we want to thank you again for your great participation and efforts to 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 2013. Two new countries, Cyprus and Georgia, have joined the Registry as of this year.

But there is more! In 2015, five papers based on Registry data have been accepted for publication at different journals and many others have been submitted or are in an advanced stage. The publication list can be found below.

Two visiting researchers came to the AMC. In March, Dinara Galiyeva from Kazakhstan visited the Registry for a project on the cardiovascular risk profile, showing a very high prevalence of cardiovascular risk factors in the European paediatric RRT population. Furthermore, Michael Böhm, a paediatric nephrologist from Austria, worked on a study on vascular access during June and July 2015.

Moreover, the relationships with ESPN working groups are well main-

tained, resulting in several proposals for collaborative future studies.

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.bonthuis@amc.uva.nl](mailto:m.bonthuis@amc.uva.nl).

**We would like to thank you again for your collaboration and hope to work together in many research projects in the hope to improve paediatric nephrology care and research in Europe.**

## Data analyses and publications

**T**he 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 2013, the overall incidence was 5.2 per million age-related population (pmarp) and ranged from 0.0, as no patients started RRT in that year, to 9.0 pmarp. The prevalence also shows a wide range from 7.1 to 85.1 pmarp. Five-year survival was 93.5% after start of RRT. The most important cause of death was infection-related.

As benchmarking reports were appreciated by the countries, the 2013 country reports again contained important benchmarking figures for several clinical parameters, providing insights on

patient performance in each country as compared to the performance of all patients in Europe.

Five papers have been accepted and published in the previous months. Three papers have been accepted by NDT. One on disparities in treatment rates in Europe<sup>1</sup>, one on growth hormone policies<sup>2</sup>, and recently a paper using survival tree models to predict graft failure in specific patient subgroups<sup>3</sup>. The first two papers showed large treatment variation across European countries.

Clinical JASN has published a paper on mineral metabolism after renal transplantation, showing a high prevalence of mineral abnormalities and an association with graft failure after

paediatric kidney transplantation.

Furthermore, a paper on post-transplant anaemia has been accepted by Pediatric Nephrology.

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 2013 and general population characteristics of countries contributing 2013 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	pmap	N	N	percent
Albania	1	1.8	565,763	2,897,365	19.5
Austria	2	1.6	1,219,363	8,451,860	14.4
Belarus	6	4.0	1,488,782	9,464,492	15.7
Bosnia and Herzegovina	5	8.2	607,160	3,507,928	17.3
Bulgaria	2	2.0	993,066	7,265,114	13.7
Croatia	4	6.3	632,089	4,254,475	14.9
Cyprus	0	0.0	140,696	861,937	16.3
Czech Republic	7	4.5	1,568,875	10,514,273	14.9
Denmark	8	8.2	973,133	5,614,929	17.3
Estonia	0	0.0	207,424	1,317,997	15.7
Finland	8	9.0	893,208	5,438,974	16.4
France	78	6.4	12,205,028	65,698,150	18.6
FYR of Macedonia	2	5.7	349,785	2,063,657	16.9
Georgia	2	2.6	760,455	4,483,230	17.0
Germany*	6	0.6	10,671,913	81,394,019	13.1
Greece	3	1.9	1,606,102	10,947,551	14.7
Hungary	5	3.5	1,428,341	9,893,081	14.4
Italy*	28	3.3	8,398,234	60,233,948	13.9
Lithuania	3	6.9	433,332	2,957,690	14.7
Malta	0	0.0	61,265	423,375	14.5
Norway	4	4.3	929,092	5,079,625	18.3
Poland	28	4.9	5,757,670	38,275,577	15.0
Portugal	7	4.6	1,536,028	10,457,296	14.7
Republic of Serbia	6	5.8	1,027,932	7,164,132	14.3
Romania	14	4.5	3,117,109	19,983,690	15.6
Russia	64	3.0	21,534,456	142,368,368	15.1
Slovakia	4	4.8	830,250	5,413,391	15.3
Slovenia	2	6.7	299,575	2,059,954	14.5
Spain	42	5.9	7,078,475	46,620,044	15.2
Sweden	13	8.0	1,628,980	9,600,380	17.0
Switzerland*	4	3.3	1,212,277	8,139,631	14.9
the Netherlands	17	5.9	2,863,997	16,804,430	17.0
Turkey*	33	1.8	18,853,496	76,147,624	24.8
United Kingdom	101	8.9	11,307,347	64,105,654	17.6
<b>Total*</b>	<b>438</b>	<b>5.2</b>	<b>84,044,778</b>	<b>590,051,993</b>	<b>15.8</b>

\* Data from the German transplantation registry are based on 18 transplantation centers. In 2013, 114 patients under the age of 21 years were transplanted. The incidence for Turkey is an underestimation of the true incidence. In Switzerland, not all patient provided informed consent resulting in an underestimation of the true incidence. In Italy, (pre-emptive) transplantation patients are not included; these numbers are an underestimation of true incidence. Therefore, Germany, Switzerland, Italy, and Turkey were excluded from the overall incidence.

**Table 2: Treatment modality at start of RRT in 2013**

Treatment modality at day 1, among patients < 15 years of age starting RRT in 2013. Patients with a pre-emptive transplantation from Italy were excluded, and all Turkish and Swiss patients.

	N	Percent	Pmarp
HD at start	180	41.1	2.14
PD at start	155	35.4	1.84
Pre-emptive transplantation	90	20.5	1.07
Unknown	13	3.0	0.15

**Table 3: PRD distribution at start of RRT in 2013**

Cause of renal failure, among patients < 15 years of age, starting RRT in 2013 according to new and old PRD coding

	N		Percent		Pmarp	
	New	Old	New	Old	New	Old
CAKUT	138	137	31.5	31.3	1.03	1.02
Glomerulonephritis	62	58	14.2	13.2	0.46	0.43
Cystic kidney disease	56	56	12.8	12.8	0.42	0.42
Hereditary nephropathy	-	29	-	6.6	-	0.22
Metabolic and tubulointerstitial disorders	21	16	4.8	3.7	0.16	0.12
Toxic/ischemic renal failure	12	9	2.7	2.1	0.09	0.07
HUS	13	13	3.0	3.0	0.10	0.10
Vascular	5	5	1.1	1.1	0.04	0.04
Pyelonephritis	-	6	-	1.4	-	0.04
Miscellaneous	90	31	20.5	7.1	0.67	0.23
Unknown	41	78	9.4	17.8	0.31	0.58

**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 2013

	N	percent
eGFR < 8 ml min <sup>-1</sup> per 1.73 m <sup>2</sup>	92	38.8
eGFR 8- 15 ml min <sup>-1</sup> per 1.73 m <sup>2</sup>	114	48.1
eGFR > 15 ml min <sup>-1</sup> per 1.73 m <sup>2</sup>	31	13.1

**Table 5: Prevalent Patients**

Prevalent paediatric patients on renal replacement therapy on the 31<sup>st</sup> of December 2013. Prevalent counts and prevalence per million age related population, by age groups.

Country	Total		Infants 0-4 years pmarp	Age Groups	
	RRT patients			Children	Adolescents
	0-14 years			5-9 years	10-14 years
	N	pmarp		pmarp	
Albania	4	7.1	0.0	5.8	13.6
Austria	44	36.1	12.6	44.6	50.1
Belarus	32	21.5	7.1	25.0	35.8
Bosnia and Herzegovina	12	19.8	37.3	0.0	26.7
Bulgaria	13	13.1	2.9	0.0	37.8
Croatia	27	42.7	42.5	24.2	60.7
Cyprus	5	35.5	20.3	43.8	43.7
Czech Republic	35	22.3	3.5	31.7	34.9
Denmark	49	50.4	16.2	48.4	83.7
Estonia	2	9.6	0.0	0.0	32.9
Finland	76	85.1	62.6	93.7	99.7
France	442	36.2	15.7	33.3	59.2
FYR of Macedonia	6	17.2	8.6	35.5	8.3
Georgia	6	7.9	3.6	4.3	16.1
Germany*	179	16.8	5.3	21.3	23.0
Greece	49	30.5	11.3	29.7	50.5
Hungary	46	32.2	10.9	28.7	56.1
Italy*	269	32.0	13.6	32.7	47.4
Lithuania	10	23.1	13.2	22.2	33.9
Malta	4	65.3	0.0	51.2	142.7
Norway	40	43.1	25.6	35.7	68.1
Poland	236	41.0	16.9	39.6	68.9
Portugal	80	52.1	12.7	52.9	85.0
Republic of Serbia	30	29.2	12.1	31.8	42.7
Romania	47	15.1	9.2	11.3	24.2
Russia	336	15.6	6.4	14.5	27.9
Slovakia	22	26.5	6.9	14.7	59.8
Slovenia	9	30.0	27.1	20.6	43.7
Spain	294	41.5	19.4	41.9	64.5
Sweden	89	54.6	24.3	52.6	91.7
Switzerland*	51	42.1	9.7	35.2	81.9
the Netherlands	129	45.0	18.8	43.5	69.9
Turkey*	334	17.7	5.5	15.4	31.7
United Kingdom	610	53.9	26.2	56.4	83.0
<b>Total*</b>	<b>2784</b>	<b>33.1</b>	<b>14.8</b>	<b>32.3</b>	<b>53.7</b>

\* Data from the German transplantation registry are based on 18 transplantation centers. In 2013, 114 patients under the age of 21 years were transplanted. The prevalence for Turkey is an underestimation of the true prevalence. In Switzerland, not all patient provided informed consent resulting in an underestimation of the true prevalence. In Italy, (pre-emptive) transplantation patients are not included; these numbers are an underestimation of true prevalence. Therefore, Germany, Switzerland, Italy, and Turkey were excluded from the overall prevalence.

**Table 5: Prevalent Patients (continued)**

Prevalent paediatric patients on renal replacement therapy on the 31<sup>st</sup> of December 2013. 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	10.2	3.7	5.3	0.0	1.8
Austria	48.0	23.6	0.8	3.3	32.0
Belarus	23.5	19.4	2.7	4.7	14.1
Bosnia and Herzegovina	25.8	13.5	16.5	1.6	1.6
Bulgaria	15.7	10.4	7.0	2.0	3.0
Croatia	55.4	29.3	4.7	22.1	15.8
Cyprus	13.8	58.4	0.0	7.1	28.4
Czech Republic	28.6	15.7	1.3	3.8	17.2
Denmark	62.2	37.9	4.1	4.1	41.1
Estonia	9.4	9.9	0.0	0.0	9.6
Finland	98.6	71.0	5.6	4.5	75.0
France	42.8	29.3	5.2	3.5	27.2
FYR of Macedonia	22.1	11.8	5.7	8.6	2.9
Georgia	10.0	5.6	3.9	2.6	1.3
Germany*	20.3	13.1	-	-	16.6
Greece	38.9	21.7	6.2	11.2	13.1
Hungary	36.8	27.3	2.1	5.6	24.5
Italy*	37.0	25.5	5.2	9.5	-
Lithuania	22.5	23.7	2.3	6.9	13.8
Malta	63.6	67.1	0.0	0.0	65.3
Norway	48.3	37.5	0.0	1.1	42.0
Poland	43.7	32.5	4.0	8.2	27.8
Portugal	62.3	41.4	2.0	13.7	36.5
Republic of Serbia	28.4	30.1	3.9	2.9	22.4
Romania	16.2	13.9	7.7	5.8	1.6
Russia	18.5	12.6	2.8	5.3	7.4
Slovakia	32.9	19.8	1.2	14.5	10.8
Slovenia	45.4	13.8	3.3	6.7	20.0
Spain	49.1	33.5	4.4	5.4	31.8
Sweden	64.5	44.2	2.5	4.3	47.3
Switzerland*	46.6	37.3	4.1	4.1	33.0
the Netherlands	55.3	34.3	3.8	3.5	37.4
Turkey*	19.6	15.7	3.1	9.2	5.1
United Kingdom	66.0	41.3	6.6	5.2	41.8
<b>Total*</b>	<b>39.2</b>	<b>26.3</b>	<b>4.6</b>	<b>7.0</b>	<b>23.3</b>

\* Data from the German transplantation registry are based on 18 transplantation centers. In 2013, 114 patients under the age of 21 years were transplanted. The prevalence for Turkey is an underestimation of the true prevalence. In Switzerland, not all patient provided informed consent resulting in an underestimation of the true prevalence. In Italy, (pre-emptive) transplantation patients are not included; these numbers are an underestimation of true prevalence. Therefore, Germany, Switzerland, Italy, and Turkey were excluded from the overall prevalence.

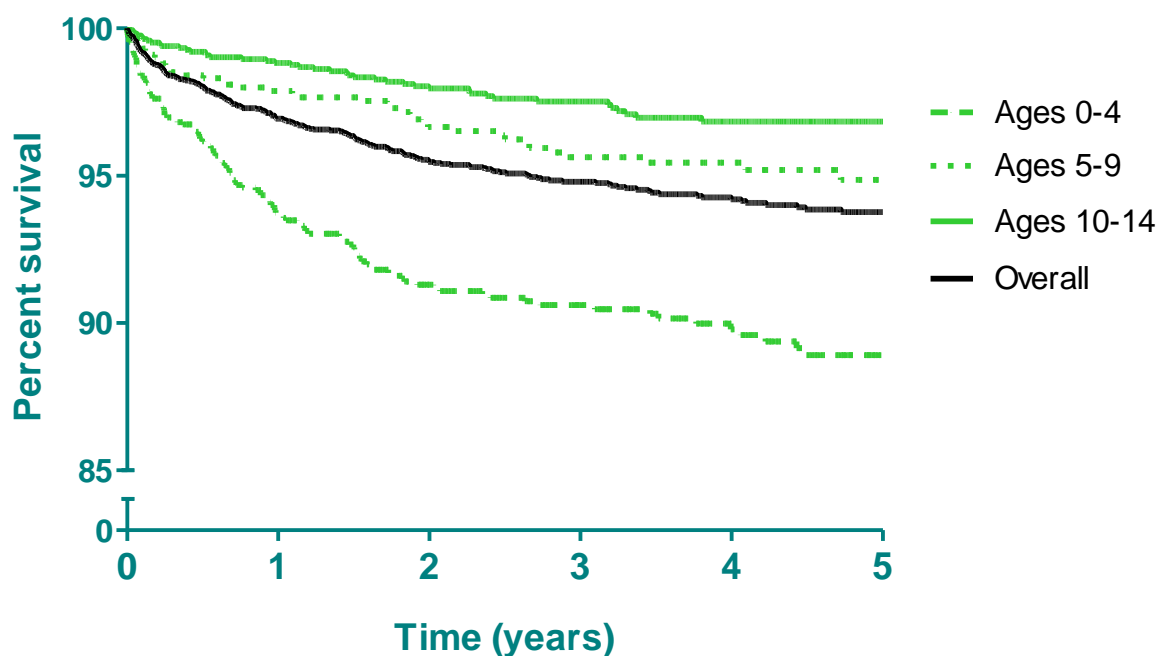
**Table 6: Hypertension and height in children on RRT**

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
<b>Blood pressure</b>		
% of patients with hypertension	46.6 (44.7 - 48.5)	26.5 (25.1 - 27.8)
Mean z-score systolic blood pressure	1.28 (1.22 - 1.35)	0.81 (0.77 - 0.86)
Mean z-score diastolic blood pressure	1.14 (1.09 - 1.20)	0.65 (0.61 - 0.67)
<b>Height</b>		
% of patients with height z-score < -2	51.5 (49.9 - 53.0)	41.8 (40.4 - 43.2)
Mean height z-score	-2.14 (-2.21 ; -2.08)	-1.84 (-1.89 ; -1.79)

**Figure 1: Two-year survival**

Incident RRT patients under the age of 15 starting RRT from 2007 onwards. Follow-up till 31st of December 2013.



## 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 2013.

	Number of deaths	Percent
<b>Myocardial ischemia and infarction</b>	1	0.4
<b>Cardiac failure</b>	19	8.0
<b>Cardiac arrest/sudden death other cause</b>	23	9.7
<b>Cerebro-vascular accident</b>	23	9.7
<b>Infection</b>	52	21.9
<b>Suicide /refusal or cessation of treatment</b>	4	1.7
<b>Treatment withdrawn</b>	5	2.1
<b>Malignant disease</b>	11	4.6
<b>Other identified cause of death</b>	54	22.8
<b>Cause of death uncertain/not determined</b>	45	19.0

### ESPN/ERA-EDTA Registry

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#### Publication list 2015

**1. Disparities in treatment rates of paediatric end-stage renal disease across Europe: insights from the ESPN/ERA-EDTA Registry.** Chesnaye NC, Schaefer F, Groothoff JW, Caskey FJ, Heaf JG, Kushnirenko S, Lewis M, Mauel R, Maurer E, Merenmies J, Shtiza D, Topaloglu R, Zaicova N, Zampetoglou A, Jager KJ, van Stralen KJ. *Nephrol Dial Transplant* 2015 Aug; 30(8): 1377-85.

**2. Considerable variations in growth hormone policy and prescription in paediatric end-stage renal**

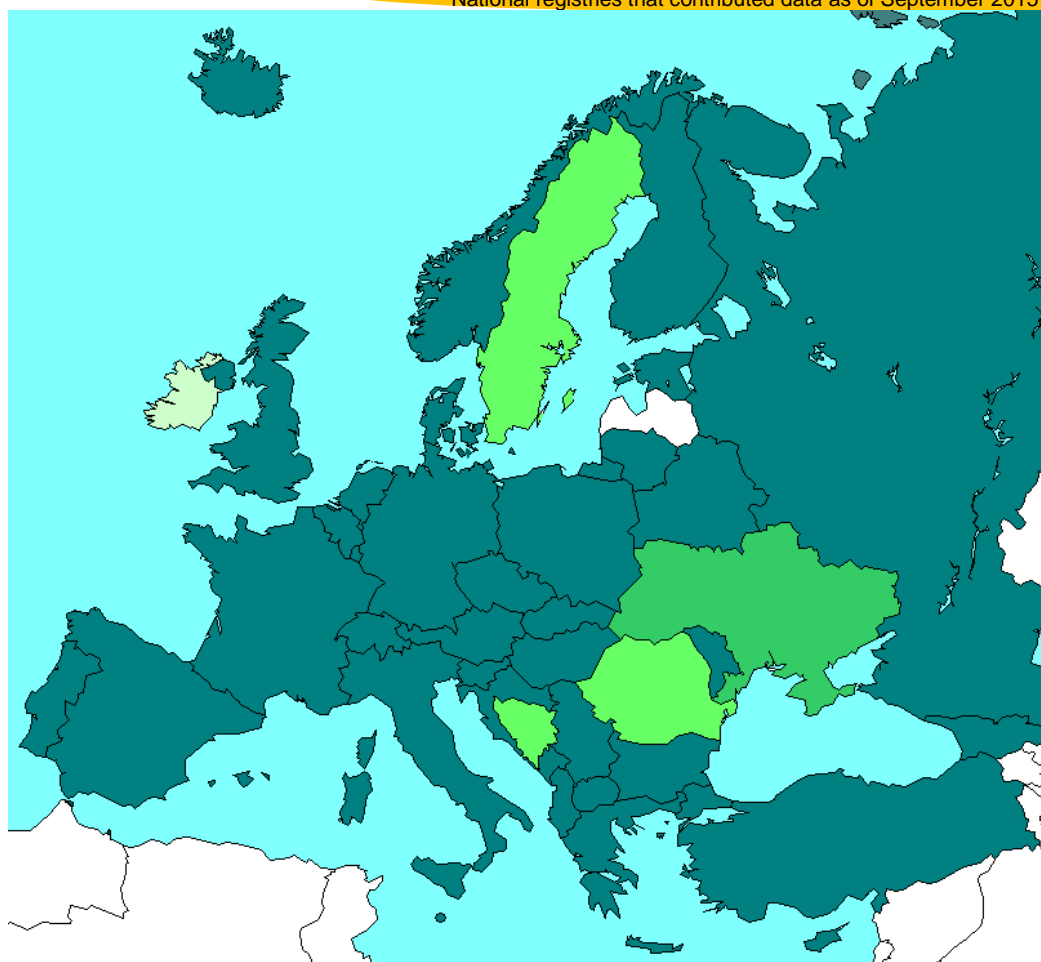
**disease across European countries- a report from the ESPN/ERA-EDTA Registry.** Van Huis M, Bonthuis M, Sahpazova E, Mencarelli F, Spasojević, Reusz G, Caldas-Afonso A, Bjerre A, Baiko S, Vondrak K, Molchanova EA, Kolvel G, Zaikova N, Böhm M, Ariceta G, Jager KJ, Schaefer F, van Stralen KJ, Groothoff JW. *Nephrol Dial Transplant* 2015 Apr 28 (ahead of print).

**3. Identification of subgroups by risk of graft failure after paediatric renal transplantation: application of survival tree models on the ESPN/ERA-EDTA Registry.** Lofaro D, Jager KJ, Abu-Hanna A, Groothoff JW, Arikoski P, Hoecker B, Roussey-Kesler G, Spasojević B, Verrina E, Schaefer F, van Stralen KJ. *Nephrol Dial Transplant* 2015 Aug 27 (ahead of print).

**4. Mineral metabolism in European children living with a renal transplant: A ESPN/ERA-EDTA Registry study.** Bonthuis M, Busutti M, van Stralen KJ, Jager KJ, Bakkaloglu S, Battelino N, Gaudarova M, Gianoglio B, Parvex P, Gomes C, Heaf JG, Podracka L, Kuzmanovaska D, Molchanova MS, Pankratenko TE, Papachristou F, Reusz G, Sanahuja MJ, Shroff R, Groothoff JW, Schaefer F, Verrina E. *Clin J Am Soc Nephrol* 2015 May 7;10(5):767-75.

**5. Anemia in children following renal transplantation- results from the ESPN/ERA-EDTA Registry.** Krischock LA, van Stralen KJ, Verrina E, Tizard EJ, Bonthuis M, Reusz G, Hussain FK, Jankauskiene A, Novljan G, Spasojević-Dimitrijeva, Podracka L, Zaller V, Jager KJ, Schaefer F. Accepted at *Pediatr Nephrol*.





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

<b>Albania</b>	D Shtiza	<b>Italy</b>	B Gianoglio, S Maringhini, F Paglialonga C Pecoraro, S Picca, E Vidal, E Verrina
<b>Austria</b>	R Kramar, G Mayer	<b>Malta</b>	V Said-Conti
<b>Belarus</b>	S Baikov, A Sukalo	<b>Moldova</b>	S Gatcan, O Berbeca, N Zaikova
<b>Belgium</b>	K van Hoeck, F Collart, JM des Grottes	<b>Montenegro</b>	S Pavićević
<b>Bosnia Herzegovina</b>	D Pokrajac	<b>Norway</b>	T Leivestad, A Bjerre
<b>Bulgaria</b>	D Roussinov	<b>Poland</b>	A Zurowska, I Zagodzón
<b>Croatia</b>	D Batinić, M Lemac, J Slavicek, D Milosevic	<b>Portugal</b>	C Mota, M Almeida, C Afonso
<b>Cyprus</b>	A Elia	<b>Romania</b>	G Mircescu, L Garneata
<b>Czech Republic</b>	T Seeman, K Vondrak	<b>Russia</b>	EA Molchanova, NA Tomilina, BT Bikbov
<b>Denmark</b>	JG Heaf	<b>Serbia</b>	M Kostic, A Peco-Antic, S Spasojevic- Dimitrijeva, G Milosevski-Lomic, D Paripovic, S Puric, D Kruscic
<b>Estonia</b>	U Toots	<b>Slovakia</b>	L Podracka, G Kolvek
<b>Finland</b>	P Finne, C Grönhagen-Riska	<b>Slovenia</b>	N Battelino, G Novljan, J Buturovic-Ponikvar
<b>France</b>	C Couchoud, M Lasalle, J Harambat	<b>Spain</b>	A Alonso Melgar and the Spanish Paediatric Registry.
<b>FYR of Macedonia</b>	E Sahpazova, N Abazi,	<b>Sweden</b>	S Schön, KG Prütz, L Bäckman, M Evans, M Stendahl, B Rippe
<b>Georgia</b>	T Davitaia	<b>Switzerland</b>	CE Kuehni, E Maurer, G Laube, S Tschumi P Parvex
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<b>Germany - KfH</b>	K Rascher, E Nüsken, L Weber, G von Gersdorff, F Schaefer	<b>Turkey</b>	R Topaloglu, A Duzova
<b>Greece</b>	N Afentakis, A Kapogiannis, N Printza, C Stefanidis	<b>Ukraine</b>	D Ivanov
<b>Hungary</b>	G Reusz, Cs Berecki, A Szabó, T Szabó, Zs Györke, E Kis	<b>United Kingdom</b>	A Hamilton, R Pruthi, F Braddon, A Causula, MD Sinha
<b>Iceland</b>	R Pálsson, V Edvardsson		
<b>Lithuania</b>	S Rudaitis, A Jankauskiene		