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# ESPN/ERA-EDTA Registry



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## An update on the Registry- November 2018



Jaap Groothoff and Jérôme Harambat

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

Currently, 36 countries are participating in the Registry, providing information on nearly 22,000 patients who started RRT before the age of 20.

Since its start in 2007, the Registry published 40 scientific papers in high-ranking medical journals. So far, in 2018, four 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 2018, two fellows joined the Registry. Michael Böhm from Vienna, Austria, started a project on the minimum weight at which infants can be transplanted.

Enrico Vidal from Padova, Italy, obtained an ERA-EDTA educational grant to perform a fellowship on antihypertensive medications in October and November 2018.

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](mailto: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 2016, the overall incidence was 5.6 per million age-related population (pmarp) and ranged from 0.0, as no patients started RRT in that year, to 15.5 pmarp. The prevalence was 34.9 and also showed a wide range from 9.7 to 80.4 pmarp. Five-year survival was 94.2% after start of RRT. Most patients died because of infections.

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

Four papers have been accepted and published during the previous months. Pediatric Nephrology accepted three papers; an educational review on survival after paediatric RRT, a paper on prune belly syndrome that demonstrated that RRT outcomes are similar to outcomes of patients receiving RRT for other forms of CAKUT, and lastly a paper on vascular access of incident HD patients. Furthermore, cJASN published our paper on recovery of kidney function. This study showed a recovery rate of 2% within 2 years after initiating maintenance dialysis. Recovery was more likely among the youngest patients and among patients with HUS, vasculitis, or ischaemic renal failure as primary kidney

disease.

Two papers are currently submitted to a scientific journal, one on post-transplant growth and one on eGFR at the start of dialysis and its association with clinical outcomes.

All these projects would not have been possible without your help and efforts, for which we are very grateful.

**Thank you all for making this possible!**

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# Table 1: Incident patients

Incident paediatric patients accepted for renal replacement therapy in 2016 and general population characteristics of countries contributing 2016 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	5	9.7	515,961	2,881,308	17.9
Austria	8	6.4	1,246,847	8,700,471	14.3
Belarus	6	3.8	1,579,277	9,504,704	16.6
Bosnia and Herzegovina	1	1.8	543,719	3,531,159	15.4
Bulgaria	2	2.0	999,613	7,127,823	14.0
Croatia	7	11.5	607,461	4,172,439	14.6
Cyprus	2	14.3	139,423	851,561	16.4
Czech Republic	7	4.3	1,635,496	10,566,334	15.5
Denmark	5	5.2	960,922	5,728,010	16.8
Estonia	0	0.0	212,526	1,315,788	16.2
Finland	3	3.4	895,101	5,495,301	16.3
France	82	6.7	12,293,404	66,859,768	18.4
FYR of Macedonia	0	0.0	344,114	2,072,400	16.6
Georgia	4	5.3	760,455	4,483,230	17.0
Germany-KFH*	43	3.9	10,964,847	82,348,668	13.3
Germany-CERTAIN*	10	0.9	10,964,847	82,348,668	13.3
Greece	4	2.6	1,555,716	10,775,971	14.4
Hungary	9	6.3	1,423,656	9,814,023	14.5
Iceland	0	0.0	66,678	335,438	19.9
Ireland	12	11.9	1,006,479	4,755,336	21.2
Italy*	25	3.0	8,232,222	60,627,497	13.6
Lithuania	1	2.4	422,934	2,868,229	14.7
Malta	1	15.5	64,455	455,356	14.2
Norway	5	5.3	935,655	5,234,518	17.9
Portugal	7	4.8	1,451,624	10,325,451	14.1
Republic of Serbia	5	4.9	1,016,587	7,058,325	14.4
Romania	12	3.9	3,061,009	19,702,332	15.5
Russia	77	3.6	21,534,456	142,368,368	15.1
Slovakia	2	2.4	836,136	5,430,798	15.4
Slovenia	3	9.8	307,492	2,065,042	14.9
Spain	50	7.1	7,015,292	46,484,065	15.1
Sweden	15	8.6	1,739,070	9,923,085	17.5
Switzerland	9	7.2	1,254,991	8,419,950	14.9
the Netherlands	18	6.4	2,790,770	16,939,923	16.6
Turkey*	62	3.3	18,906,001	79,277,963	23.8
Ukraine	26	4.0	6,535,536	42,414,905	15.4
United Kingdom	104	8.9	11,67,832	65,648,054	17.8
<b>Total*</b>	<b>492</b>	<b>5.6</b>	<b>87,429,687</b>	<b>544,399,695</b>	<b>16.1</b>

\* In 2016, 110 patients under the age of 21 years were transplanted in 18 transplant centres 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 2016

Treatment modality at day 1, among patients < 15 years of age starting RRT in 2016.  
Patients from Germany, Italy, and Turkey are excluded.

	<b>N</b>	<b>Percent</b>	<b>Pmarp</b>
HD at start	204	41.4	2.35
PD at start	187	38.0	2.15
Pre-emptive transplantation	100	20.3	1.15
Unknown	1	0.2	0.01

## Table 3: PRD distribution at start of RRT in 2016

Cause of renal failure, among patients < 15 years of age, starting RRT in 2016 according to new and old PRD coding.

	<b>N</b>		<b>Percent</b>		<b>Pmarp</b>	
	<b>New</b>	<b>Old</b>	<b>New</b>	<b>Old</b>	<b>New</b>	<b>Old</b>
CAKUT	179	146	36.4	29.7	2.05	1.67
Glomerulonephritis	98	83	19.9	16.9	1.12	0.95
Cystic kidney disease	50	55	10.1	11.2	0.57	0.63
Hereditary nephropathy	-	37	-	7.5	-	0.42
Metabolic and tubulointerstitial disorders	23	7	4.7	1.4	0.26	0.08
Toxic/ischemic renal failure	11	6	2.2	1.2	0.13	0.07
HUS	24	24	4.9	4.9	0.27	0.27
Vascular	9	7	1.8	1.4	0.10	0.08
Miscellaneous	89	83	18.1	16.9	1.02	0.95
Unknown	9	44	1.0	8.9	0.10	0.50

## 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 2016.

	<b>N</b>	<b>Percent</b>
eGFR<8 ml min <sup>-1</sup> per 1.73 m <sup>2</sup>	81	36.3
eGFR 8- 15 ml min <sup>-1</sup> per 1.73 m <sup>2</sup>	111	49.8
eGFR>15 ml min <sup>-1</sup> per 1.73 m <sup>2</sup>	31	13.9

# Table 5: Prevalent Patients

Prevalent paediatric patients on renal replacement therapy on the 31<sup>st</sup> of December 2016. Prevalent counts and prevalence per million age related population, by age groups.

Country	Total RRT		Age Groups		
	0-14 years		Infants	Children	Adolescents
	N	pmarp	0-4 years pmarp	5-9 years pmarp	10-14 years pmarp
Albania	5	9.7	6.0	6.3	15.8
Austria	52	41.7	26.4	41.4	57.2
Belarus	38	24.1	5.0	31.6	40.2
Bosnia and Herzegovina	10	18.4	17.2	17.0	20.8
Bulgaria	10	10.0	3.0	11.5	15.7
Croatia	31	51.0	25.5	57.2	69.5
Cyprus	10	71.7	63.5	104.6	45.1
Czech Republic	45	27.5	12.7	15.2	59.1
Denmark	39	40.6	16.9	42.4	59.9
Estonia	4	18.8	0.0	0.0	61.2
Finland	72	80.4	79.0	61.6	101.4
France	470	38.2	19.7	35.2	58.6
FYR of Macedonia	5	14.5	0.0	34.8	8.8
Georgia	15	19.7	7.1	26.0	28.1
Germany-KFH*	156	14.2	18.2	10.0	14.4
Germany-CERTAIN*	249	22.7	8.1	22.3	37.7
Greece	53	34.1	6.3	34.7	58.5
Hungary	56	39.3	13.1	31.2	72.3
Iceland	3	45.0	0.0	42.5	93.0
Ireland	76	75.5	24.3	75.8	128.0
Italy*	253	30.7	15.4	30.6	44.5
Lithuania	9	21.3	6.6	28.3	30.7
Malta	2	31.0	0.0	46.6	48.7
Norway	53	56.6	29.6	46.6	93.7
Portugal	73	50.3	13.9	54.8	75.9
Republic of Serbia	30	29.5	6.1	27.0	53.4
Romania	49	16.0	4.2	15.3	27.6
Russia	440	20.4	9.4	20.3	33.9
Slovakia	16	19.1	10.5	20.9	26.6
Slovenia	10	32.5	47.0	9.2	43.3
Spain	333	47.5	17.5	47.0	75.5
Sweden	100	57.5	28.7	55.5	90.5
Switzerland	71	56.6	32.5	35.7	103.9
the Netherlands	128	45.9	16.0	65.6	53.7
Turkey*	297	15.7	7.6	10.1	29.9
Ukraine	86	13.2	4.5	10.7	25.8
United Kingdom	653	55.9	27.4	56.5	86.9
<b>Total*</b>	<b>3047</b>	<b>34.9</b>	<b>15.7</b>	<b>34.4</b>	<b>55.5</b>

\* In 2016, 110 patients under the age of 21 years were transplanted in 18 transplant centres in Germany. In Italy, (pre-emptive) transplantation patients are not included; these numbers are an underestimation of the 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 31<sup>st</sup> of December 2016. Prevalent counts and prevalence per million age related population, by gender and treatment modality.

Country	Gender		Treatment Modality		
	Males 0-14 years pmarp	Female 0-14 pmarp	HD 0-14 years pmarp	PD 0-14 years pmarp	Transplantation 0-14 years pmarp
Albania	3.7	16.2	5.8	0.0	3.9
Austria	51.5	31.4	4.8	3.2	33.7
Belarus	28.3	15.7	2.5	3.8	17.7
Bosnia and Herzegovina	25.1	11.3	12.9	0.0	5.5
Bulgaria	13.6	6.2	3.0	2.0	5.0
Croatia	54.4	47.4	1.6	31.3	18.1
Cyprus	55.9	88.5	7.2	35.9	28.7
Czech Republic	33.4	21.3	3.1	4.9	19.6
Denmark	50.7	29.9	2.1	4.2	33.3
Estonia	18.3	19.3	0.0	0.0	18.8
Finland	98.4	61.7	1.1	4.5	74.9
France	44.9	31.3	6.9	3.7	27.7
FYR of Macedonia	16.9	12.0	5.8	5.8	2.9
Georgia	22.5	16.7	5.3	10.5	3.9
Germany-KFH*	14.4	10.1	4.6	9.6	-
Germany-CERTAIN*	32.1	12.8	-	-	22.5
Greece	42.6	23.8	9.0	11.6	13.5
Hungary	47.9	30.3	2.8	4.9	31.6
Iceland	88.1	0.0	0.0	0.0	45.0
Ireland	83.6	67.1	7.9	10.9	56.6
Italy*	35.9	24.5	4.6	7.5	-
Lithuania	18.5	24.3	0.0	9.5	11.8
Malta	30.0	32.1	0.0	0.0	31.0
Norway	64.7	48.2	0.0	2.1	54.5
Portugal	57.9	42.4	1.4	9.6	39.3
Republic of Serbia	28.7	30.4	7.9	3.0	18.7
Romania	16.5	15.5	10.1	4.6	1.3
Russia	24.3	16.4	5.0	9.0	6.5
Slovakia	18.7	19.7	7.2	7.2	4.8
Slovenia	37.9	26.8	9.8	6.5	16.3
Spain	58.1	36.2	5.0	4.0	38.2
Sweden	67.1	47.4	2.3	8.1	47.2
Switzerland*	41.9	34.4	2.4	7.2	28.7
the Netherlands	55.3	36.0	3.2	2.1	40.1
Turkey*	16.3	15.1	2.4	6.9	6.3
Ukraine	13.7	12.6	3.8	2.8	6.6
United Kingdom	70.1	41.1	7.5	7.2	40.9
<b>Total*</b>	<b>41.1</b>	<b>27.5</b>	<b>5.4</b>	<b>6.1</b>	<b>22.5</b>

\* In 2016, 110 patients under the age of 21 years were transplanted in 18 transplant centres 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. In Switzerland, not all patients provided informed consent resulting in an underestimation of the true prevalence. Therefore, Germany, Italy, Turkey, and Switzerland were excluded from the overall prevalence.

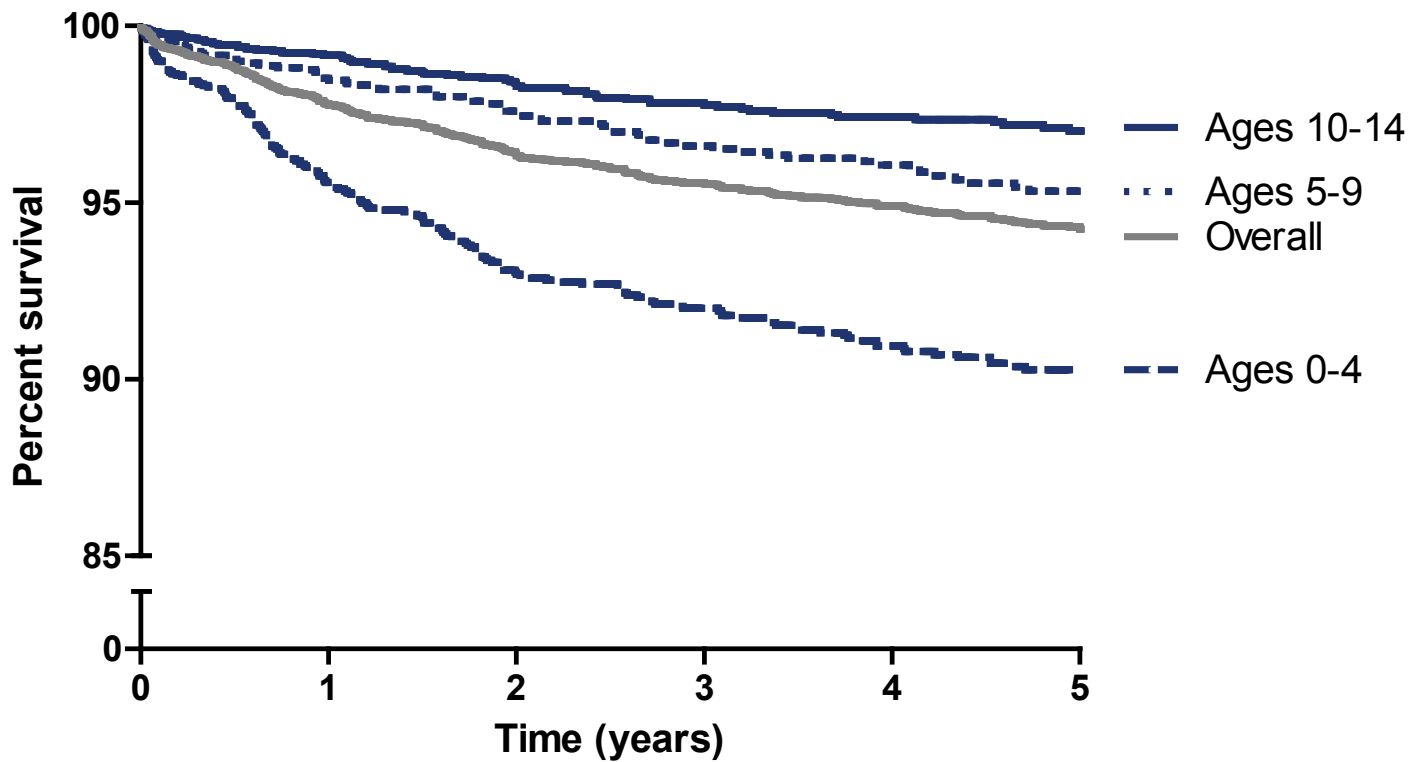
## Table 6: Hypertension and height in children on RRT

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 (45.0-48.3)	28.7 (27.5-29.9)
Mean z-score systolic blood pressure	1.34 (1.26-1.43)	0.83 (0.79-0.86)
Mean z-score diastolic blood pressure	1.17 (1.13-1.21)	0.67 (0.64-0.70)
<b>Height</b>		
% of patients with height z-score < -2	45.8 (44.6-47.0)	38.5 (37.3-39.7)
Mean height z-score	-1.83 (-1.88; -1.77)	-1.72 (-1.76; -1.67)

### Figure 1: Five-year survival

Incident RRT patients under the age of 15 starting RRT from 2007 onwards. Follow-up till 31st of December 2016.



## Table 7: Causes of Death

Causes of death according to the ERA-EDTA coding list. Incident RRT patients under the age of 15 starting RRT from 2007 onwards are included. Follow-up till 31<sup>st</sup> of December 2016

Cause of death	Number of deaths	Percent
Myocardial ischemia and infarction	2	0.6
Cardiac failure	31	8.9
Cardiac arrest/sudden death other cause	36	10.3
Cerebro-vascular accident	23	6.6
Infection	71	20.3
Suicide/refusal or cessation of treatment	5	1.4
Treatment withdrawn	6	1.7
Malignant disease	11	3.1
Other identified cause of death	60	17.1
Cause of death uncertain/not determined	105	30.0

### ESPN/ERA-EDTA Registry Scientific Committee

Jaap Groothoff, the Netherlands\*  
 Jérôme Harambat, France\*  
 Elena Levtchenko, Belgium  
 Ziad Massy, France  
 Dieter Haffner, Germany  
 Constantinos Stefanidis, Greece  
 Anna Bjerre, Norway  
 Kitty Jager, The Netherlands

\* ESPN representatives on the ERA-EDTA Registry Committee

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### Publication list 2018

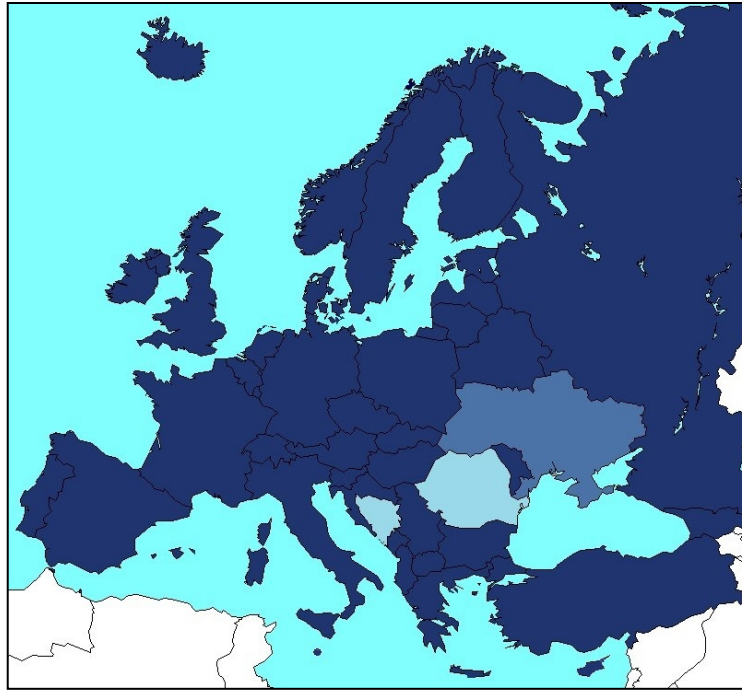
**1. Outcomes of renal replacement therapy in boys with prune belly syndrome: findings from the ESPN/ERA-EDTA Registry.** Yalcinkaya F, Bonthuis M, Doganay Erdogan B, van Stralen KJ, Baiko S, Chehade H, Maxwell H, Montini G, Rönnholm K, Schwartz Sørensen S, Ulinski T, Verrina E, Weber S, Harambat J, Schaefer F, Jager KJ, Groothoff JW. *Pediatr Nephrol* 2018 Jan;33(1):117-124

**2. Survival in children requiring chronic renal replacement therapy.** Chesnaye NC, van Stralen KJ, Bonthuis M, Harambat J, Groothoff JW, Jager KJ. *Pediatr Nephrol* 2018 Apr;33(4):585-594

**3. Recovery of kidney function in children treated with maintenance dialysis.** Bonthuis M, Harambat J, Bérard E, Cransberg K, Duzova A, Garneata L, Herthelius M, Lungu AC, Jahnukainen T, Kaltenegger L, Aricieta G, Maurer E, Palsson R, Sinha MD, Testa S, Groothoff JW, Jager KJ. *Clin J Am Soc Oct 8;13(10):1510-1516.*

**4. Hemodialysis vascular access and subsequent transplantation: A report from the ESPN/ERA-EDTA Registry.** Boehm M, Bonthuis M, Noordzij M, Harambat J, Groothoff JW, Alonso Melgar A, Buturovic J, Dusunsel R, Fila M, Jander A, Koster-Kamphuis L, Novljan G, Ortega PJ, Paglialonga F, Saravo MT, Stefanidis CJ, Aufricht C, Jager KJ, Schaefer F. *Accepted by 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 to the Registry

<b>Albania</b>	D Shtiza	<b>Italy</b>	E Vidal, E Verrina
<b>Austria</b>	R Kramar	<b>Latvia</b>	H Čerņevskis, V Kuzema
<b>Belarus</b>	S Baiko, A Sukalo	<b>Lithuania</b>	A Jankauskiene, S Rudaitis
<b>Belgium</b>	K van Hoeck and the Centre contributors to the Belgian Registry Committee	<b>Malta</b>	V Said-Conti
<b>Bosnia Herzegovina</b>	D Pokrajac	<b>Moldova</b>	S Gatcan, O Berbeca, N Zaikova, N Revenco
<b>Bulgaria</b>	D Roussinov	<b>Montenegro</b>	S Pavićević
<b>Croatia</b>	D Milosevic, M Ban, J Slavicek, D Arapovic, S Abdovic	<b>Norway</b>	A Åsberg, AV Reisæter, A Bjerre
<b>Cyprus</b>	A Elia	<b>Poland</b>	A Zurowska, I Zagodzdon
<b>Czech Republic</b>	T Seeman, K Vondrak	<b>Portugal</b>	C Mota, R Stone, C Simão
<b>Denmark</b>	JG Heaf	<b>Romania</b>	G Mircescu, L Garneata
<b>Estonia</b>	Ü Toots	<b>Russia</b>	EA Molchanova, NA Tomilina
<b>Finland</b>	P Finne, A Pylsy, P-H Groop	<b>Serbia</b>	M Kostić, B Spasojević, M Cvetković, I Gojković, D Paripović, G Miloševski-Lomić
<b>France</b>	C Couchoud, M Lassalle, E Berard	<b>Slovakia</b>	L Podracka, G Kolvek
<b>FYR of Macedonia</b>	E Sahpazova, N Abazi	<b>Slovenia</b>	N Battelino, G Novljan, J Buturovic-Ponikvar
<b>Georgia</b>	T Davitaia	<b>Spain</b>	A Alonso Melgar and the Spanish Paediatric Registry.
<b>Germany - CERTAIN</b>	K Krupka, B Höcker, L Pape, B Tönshoff	<b>Sweden</b>	KG Prütz, M Stendahl, M Evans, S Schön
<b>Germany - KfH</b>	K Rascher, E Nüsken, L Weber, G von Gersdorff, Jörg Dötsch, F Schaefer	<b>Switzerland</b>	M Segelmark, T Lundgren
<b>Greece</b>	N Afentakis, A Kapogiannis, A Mitsioni, N Printza		GF Laube, CE Kuehni, E Maurer, H Chehade, C Rudin
<b>Hungary</b>	G Reusz, Cs Berecki, A Szabó, T Szabó, A Barczy, O Lakatos, E Kis	<b>The Netherlands</b>	L Heuveling and MH Hemmeler on behalf of the Nefrovisie foundation, and JW Groothoff all centres participating in the RICHQ-study
<b>Iceland</b>	R Palsson, V Edvardsson	<b>Turkey</b>	S Bakkaloglu
<b>Ireland</b>	A Awan, T Raftery, C Sweeney, N Dolan	<b>Ukraine</b>	DD Ivanov, SP Fomina
<b>Italy</b>	B Gianoglio, C Corrado, I Guzzo, F Paglialonga, C Pecoraro,	<b>United Kingdom</b>	L Plumb, F Braddon, A Casula, MD Sinha, H Maxwell