

An update on the Registry



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As members of the ESPN/ERA-EDTA Registry committee we want to thank you again for your fantastic participation and enthusiasm for the Registry. Currently, 36 countries are participating in the registry, providing information on 10,000 patients who started RRT before the age of 20, between 1997 and 2011. But there is more! In 2013, already

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

Also this year, many visiting researchers came to the AMC. Early this year, Karlijn Meys visited the AMC for a project on eGFR decline in transplantation patients. She found that female adolescents (16-20 years) seem to have a poor graft survival. During a three month period, Marco Busutti, a medical student from Bologna, Italy, performed his scientific internship at the Registry. He worked on a project about calcium phosphate metabolism. Three other researchers are planning on visiting the Registry later this year. Enrico Vidal will work on a project on infant dialysis. Tuula

Höittä will study Finnish type nephropathy, while Djalila Mekhali will work on ARPKD. 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 speak to us during the IPNA conference, 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 six subsequent years. In 2011, the median incidence was 4.8 per million age-related population (pmarp) and ranged from 0, as no patients started RRT in that year, to 15.1 pmarp. The prevalence also shows a wide range from 5.0 to 84.4 pmarp. Five-year survival was 93.7% after start of RRT. The most important cause of death was infection related. The 2011 country reports contained important benchmarking figures for several clinical parameters. In this way, for each country the patient's performance for these clinical parameters could

be compared to the performance of all patients in Europe.

Furthermore, seven papers have been accepted and published in the previous months. NDT published our paper on underweight and overweight¹ for a special issue on obesity. In January, our paper on graft loss in recurrent diseases was printed.² This summer, PLoS ONE accepted our methodological paper on whether it is more appropriate to expressing BMI according to age or height-age.³ This paper is published open access. We also wrote a paper on transplantation policies in Europe, showing large variation across the countries⁴, which has been accepted by AJT. cJASN accepted two of our papers; one on Congenital

Anomalies of the Kidney and Urinary Tract,⁵ showing that this is not only a pediatric problem, and one on final height. In this latter paper we show that major improvements have been achieved in recent decades with respect to growth. Finally, NDT also accepted a paper on the lipid profile, showing the very high prevalence of elevated triglyceride and non-HDL levels, combined with very poor HDL levels.

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 2011 and general population characteristics of countries contributing 2011 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	1	1.7	596,341	2,829,337	21.1
Austria	10	8.1	1,229,561	8,423,635	14.6
Belarus	7	4.9	1,421,400	9,473,171	15.0
Belgium	4	2.1	1,864,930	10,993,625	17.0
Bosnia and Herzegovina	4	6.6	607,160	3,507,928	17.3
Bulgaria	3	3.1	977,543	7,348,327	13.3
Croatia	4	6.1	660,034	4,385,962	15.0
Czech Republic	10	6.5	1,531,503	10,496,088	14.6
Denmark	4	4.0	1,003,322	5,627,477	17.8
Estonia	1	4.8	206,676	1,339,825	15.4
Finland	6	6.8	888,329	5,388,272	16.5
France	62	5.2	11,927,557	64,723,538	18.4
FYR of Macedonia	1	2.8	356,348	2,058,088	17.3
Germany*	17	2.0	10,886,645	81,797,672	13.3
Greece	5	3.1	1,625,194	11,300,410	14.4
Hungary	7	4.8	1,449,526	9,971,726	14.5
Iceland	1	15.1	66,438	319,013	20.8
Italy*	26	3.1	8,520,714	60,723,569	14.0
Lithuania	1	2.2	451,298	3,030,173	14.9
Malta	0	0.0	61,952	416,674	14.9
Moldova	1	1.7	581,419	3,559,986	16.3
Norway	10	10.8	922,642	4,953,087	18.6
Poland	35	6.0	5,837,371	38,534,156	15.1
Portugal	15	9.6	1,567,964	10,556,999	14.9
Romania	20	6.2	3,225,135	21,384,832	15.1
Russia	66	3.1	21,534,456	142,368,368	15.1
Serbia	4	3.7	1,088,634	7,258,745	15.0
Slovakia	3	3.6	832,064	5,398,384	15.4
Slovenia	1	3.4	292,501	2,052,843	14.2
Spain	46	6.5	7,038,452	47,227,914	14.9
Sweden	12	7.6	1,574,614	9,449,212	16.7
Switzerland	10	8.4	1,194,649	7,954,662	15.0
the Netherlands	16	5.5	2,901,867	16,693,073	17.4
Turkey	70	3.7	18,882,578	74,223,628	25.4
Ukraine	20	3.1	6,513,760	45,525,730	14.3
United Kingdom	91	8.3	10,962,918	62,752,458	17.5
Total*	577	4.4	131,283,495	804,048,587	16.3

* Data from Germany are only based on transplantation patients from 15 out of 20 transplantation centers, dialysis patients are not included. Each year, around 120 patients are transplanted, of which 16% pre-emptively. In Italy, (pre-emptive) transplantation patients are not included. Therefore these numbers are an underestimation of true incidence.

Table 2: Treatment modality at start of RRT

Treatment modality at day 1, among patients < 15 years of age starting RRT in 2011. Patients with a pre-emptive transplantation from Italy were excluded.

	N	percent	pmarp
HD at start	302	40.6	2.30
PD at start	296	39.8	2.25
Pre-emptive transplantation	145	19.5	1.10

Table 3: PRD distribution at start of RRT

Cause of renal failure, among patients < 15 years of age, starting RRT in 2011

	N	percent	pmarp
Glomerulonephritis	97	16.3	0.74
Congenital anomalies of the kidney and urinary tract	234	39.4	1.78
Cystic kidney disease	74	12.5	0.56
Hereditary Nephropathy	41	6.9	0.31
Ischemic renal failure	6	1.0	0.05
HUS	18	3.0	0.14
Metabolic Disorders	12	2.0	0.09
Vasculitis	4	0.7	0.03
Pyelonephritis	13	2.2	0.10
Miscellaneous	48	8.1	0.37
Unknown	47	7.9	0.36

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 2011

	N	percent
eGFR<8 ml min ⁻¹ per 1.73 m ²	101	38.4
eGFR 8- 15 ml min ⁻¹ per 1.73 m ²	121	46.0
eGFR>15 ml min ⁻¹ per 1.73 m ²	41	15.6

Table 5: Prevalent Patients

Prevalent paediatric patients on renal replacement therapy on the 31st of December 2011. Prevalent counts and prevalence per million age related population, by age groups.

Country	Total RRT patients 0-14 years		Infants 0-4 years pmarp	Age Groups	
	N	pmarp		Children 5-9 years	Adolescents 10-14 years
					pmarp
Albania	3	5.0	6.0	0.0	8.4
Austria	52	42.3	35.6	24.6	65.1
Belarus	32	22.5	15.2	11.3	42.0
Belgium	86	46.1	37.3	16.4	85.0
Bosnia and Herzegovina	10	16.5	6.2	18.0	22.3
Bulgaria	10	10.2	8.7	0.0	22.3
Croatia	20	30.3	23.3	24.3	41.7
Czech Republic	44	28.7	39.0	8.2	37.6
Denmark	45	44.9	27.6	24.1	81.3
Estonia	2	9.7	25.7	0.0	0.0
Finland	75	84.4	79.4	54.9	118.7
France	417	35.0	36.1	14.4	54.7
FYR of Macedonia	8	22.4	8.7	17.5	39.4
Germany*	192	17.6	27.7	12.1	26.6
Greece	51	31.4	26.2	22.5	46.2
Hungary	42	29.0	27.3	14.5	45.0
Iceland	4	60.2	42.5	47.0	92.5
Italy*	259	30.4	31.0	16.5	43.8
Lithuania	10	22.2	13.3	14.7	36.5
Moldova	4	6.9	0.0	5.4	14.8
Malta	4	64.6	50.4	51.4	88.4
Norway	41	44.4	54.9	30.1	47.9
Poland	237	40.6	35.8	21.0	63.9
Portugal	76	48.5	51.9	28.6	64.0
Romania	40	12.4	10.3	5.7	20.9
Russia	290	13.5	10.2	6.7	24.6
Serbia	30	27.6	26.3	10.5	46.4
Slovakia	23	27.6	14.0	3.8	63.9
Slovenia	12	41.0	18.5	10.9	97.0
Spain	295	41.9	38.3	20.2	69.5
Sweden	81	51.4	42.5	40.1	74.0
Switzerland	51	42.7	40.2	13.0	73.0
the Netherlands	134	46.2	42.3	26.6	68.7
Turkey	302	16.0	10.7	7.9	28.5
Ukraine	38	5.8	2.4	2.0	13.9
United Kingdom	605	55.2	49.8	27.8	88.7
Total*	3433	26.1	23.1	13.2	42.1

* Data from Germany are only based on transplantation patients from 15 out of 20 transplantation centers, dialysis patients are not included. Each year, around 120 patients are transplanted, of which 16% pre-emptively. In Italy, (pre-emptive) transplantation patients are not included. Therefore 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 2011. 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	6.4	3.5	5.0	0.0	0.0
Austria	57.1	26.7	3.3	0.8	38.2
Belarus	17.8	27.5	2.1	6.3	13.4
Belgium	48.3	43.9	8.6	7.0	30.6
Bosnia and Herzegovina	16.1	16.8	9.9	1.6	4.9
Bulgaria	17.9	2.1	5.1	2.0	3.1
Croatia	32.5	28.0	4.5	9.1	16.7
Czech Republic	28.0	29.5	3.9	10.4	14.4
Denmark	62.3	26.6	2.0	4.0	37.9
Estonia	9.4	10.0	0.0	0.0	9.7
Finland	88.1	80.6	2.3	6.8	75.4
France	41.6	28.0	5.6	3.8	18.9
FYR of Macedonia	27.2	17.4	5.6	14.0	2.8
Germany*	27.7	16.4			19.7
Greece	33.4	27.9	3.7	12.9	14.8
Hungary	33.6	24.1	2.1	9.0	17.2
Iceland	58.9	61.5	15.1	15.1	30.1
Italy*	36.5	23.9	2.7	6.6	
Lithuania	21.6	22.8	6.6	6.6	8.9
Moldova	6.7	7.1	3.4	1.7	0.0
Malta	62.8	66.4	0.0	0.0	64.6
Norway	50.8	37.8	3.3	5.4	35.8
Poland	45.8	31.3	2.9	7.9	27.8
Portugal	56.1	40.5	2.6	15.3	30.6
Romania	11.5	13.4	5.3	5.3	1.9
Russia	14.9	12.0	2.4	4.2	6.7
Serbia	28.6	26.5	4.6	4.6	18.4
Slovakia	32.8	22.2	3.6	14.4	8.4
Slovenia	53.2	28.2	6.8	10.3	23.9
Spain	49.7	33.6	3.7	4.8	33.2
Sweden	65.5	36.6	5.1	5.1	41.3
Switzerland	47.3	37.9	1.7	5.0	34.3
the Netherlands	56.6	35.3	4.1	5.9	35.8
Turkey	17.4	14.5	2.5	8.5	5.0
Ukraine	6.0	5.7	3.1	1.7	1.1
United Kingdom	65.8	44.1	4.9	7.5	42.1
Total*	32.0	22.8	3.3	5.5	16.4

* Data from Germany are only based on transplantation patients from 15 out of 20 transplantation centers, dialysis patients are not included. Each year, around 120 patients are transplanted, of which 16% pre-emptively. In Italy, (pre-emptive) transplantation patients are not included. Therefore these numbers are an underestimation of true prevalence.

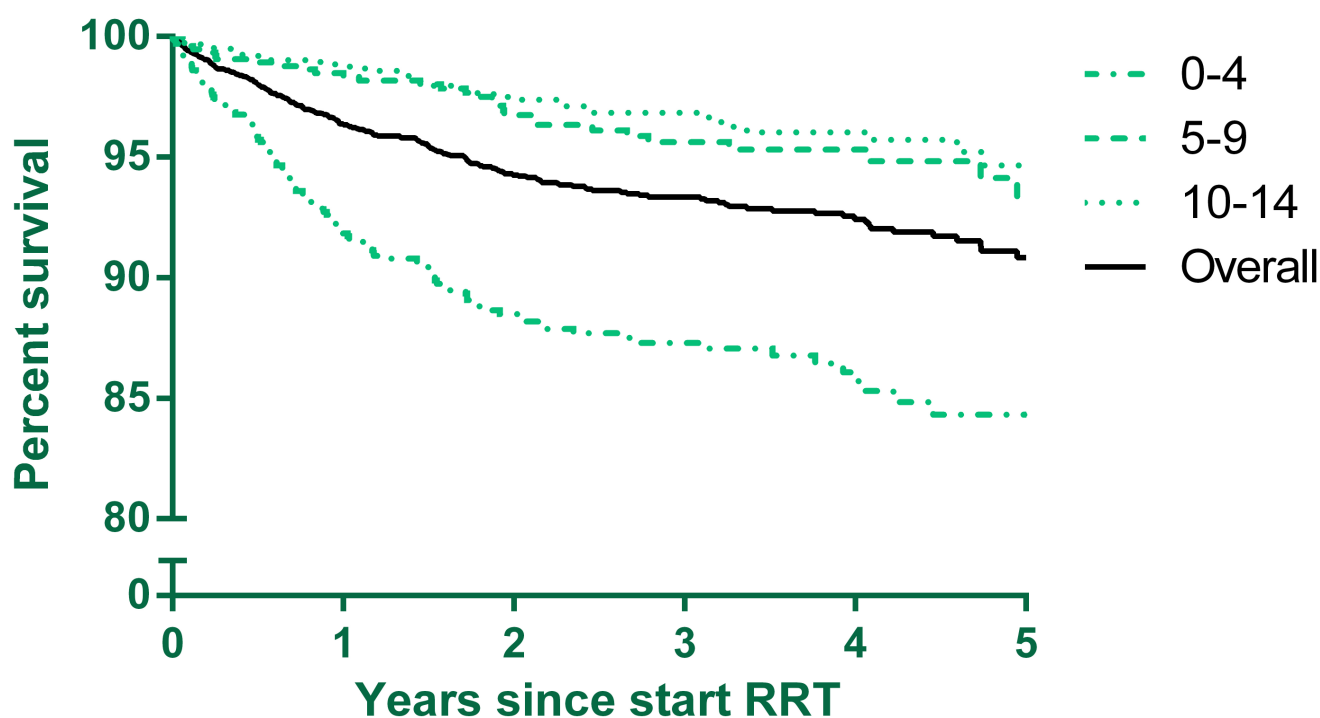
Table 6: hypertension and height in children on RRT

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

	Dialysis	Transplantation
Blood pressure		
% of patients with hypertension	46.4 (42.6;50.2)	23.3 (21.2;25.4)
Mean z-score systolic blood pressure	1.23 (1.10;1.35)	0.69 (0.63;0.74)
Mean z-score diastolic blood pressure	1.16 (1.06;1.25)	0.50 (0.45;0.54)
Height		
% of patients with a height z-score below 2	56.8 (53.4;60.0)	39.5 (37.3;41.8)
Mean height z-score	-2.39 (-2.51;-2.26)	-1.73 (-1.79;-1.66)

Figure 1: two-year survival

Incident RRT patients under the age of 15 starting RRT in 2007. Follow-up till 31st of December 2011.



Data included:

Austria, Belarus, Belgium, 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 in 2007. Follow-up till 31st of December 2011.

	Number of deaths	Percent
Cardiac failure	8	4.8
Myocardial ischemia and infarction	1	0.6
Cardiac arrest/sudden death other cause	8	4.8
Cerebro-vascular accident	11	6.7
Infection	34	20.6
Suicide /refusal or cessation of treatment	1	0.6
Malignant disease	5	3.0
Treatment withdrawn	2	1.2
Other identified cause of death	14	8.5
Cause of death uncertain/not determined	81	49.1

ESPN/ERA-EDTA Registry Scientific Committee

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Publication list ESPN/ERA-EDTA registry 2013

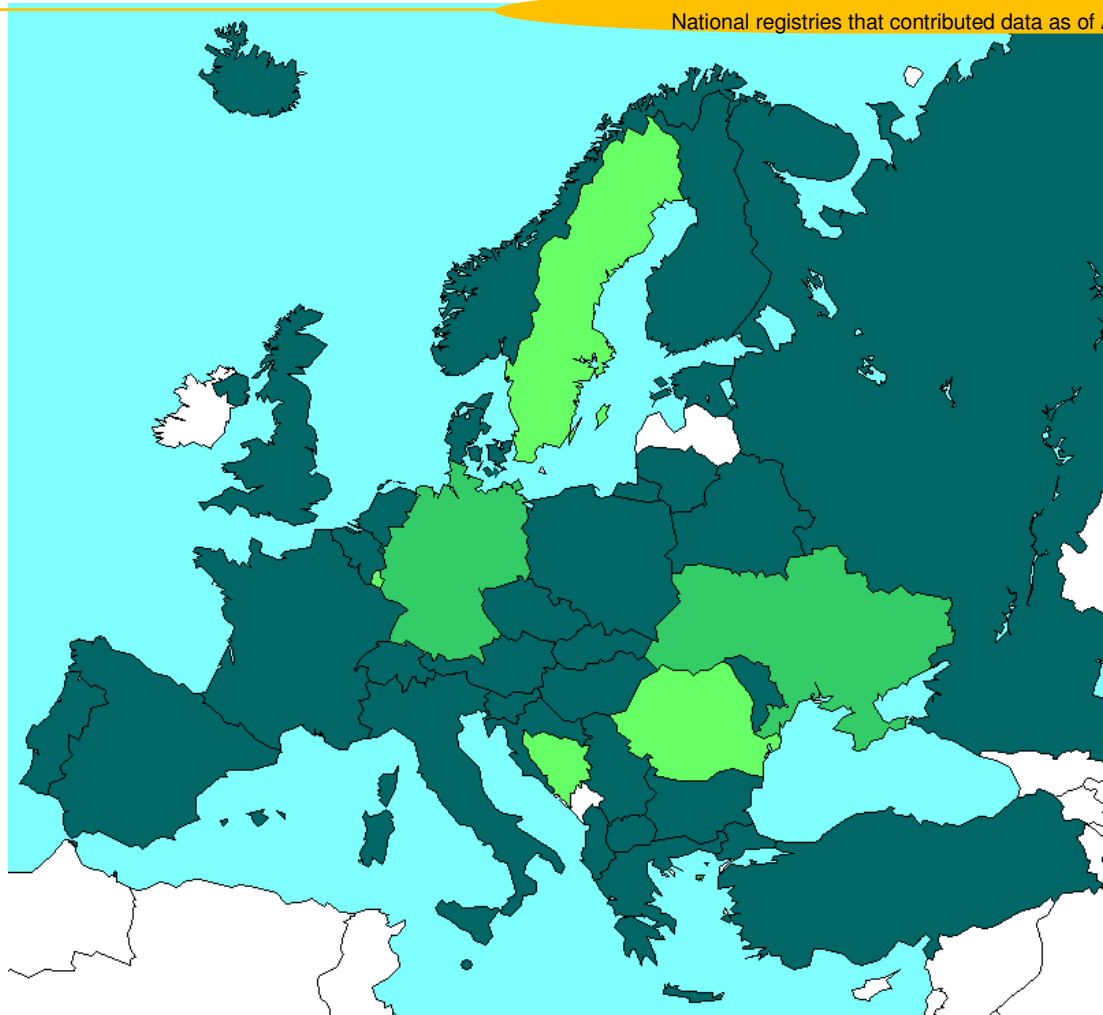
1. Underweight, overweight, and obesity in paediatric dialysis and renal transplant patients. Bonthuis M, van Stralen KJ, Verrina E, Groothoff JW, Alonso Melgar A, Edefonti A, Fischbach M, Mendes P, Molchanova EA, Paripović D, Peco-Antic A, Printza N, Rees L, Rubik J, Stefanidis CJ, Sinha MD, Zagozdzon I, Jager KJ, Schaefer F; NDT 2013; 0:1-10

2. Impact of graft loss among kidney diseases with a high risk of recurrence in the paediatric population. van Stralen KJ, Verrina E, Belingheri M, Dudley J, Dusek J, Grenda R, Macher MA, Puretic Z, Rubik J, Rudaitis S, Rudin C, Schaefer F, Jager KJ; NDT 2013; 28:1031-8.

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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	Malta	V Said-Conti
Austria	R Kramar, R Oberbauer	Moldova	S Gatcan, O Berbeca, N Zaikova
Belarus	S Baiko, A Sukalo	Montenegro	S Pavičević
Belgium	K van Hoeck, F Collart, JM des Grottes	Norway	T Leivestad, A Bjerre
Bosnia Herzegovina	D Pokrajac, H Resić, B Prnjavorac	Poland	A Zurowska, I Zagozdzon
Bulgaria	D Roussinov	Portugal	C Mota, M Almeida, C Afonso
Croatia	D Batinić, M Lemac, J Slavicek	Romania	G Mircescu, L Garneata, E Podgoreanu
Czech Republic	T Seeman, K Vondrak	Russia	EA Molchanova, NA Tomilina, BT Bikbov
Denmark	JG 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.
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Germany	F Schaefer, G Gernsdorf, C Barth, C Scholz, B Tönshoff, K Krupka, B Höcker, L Pape	Switzerland	CE Kuehni, G Laube, E Maurer, G Simoneti, E Girardin
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Iceland	R Pálsson, V Edvardsson	Ukraine	D Ivanov
Italy	B Gianoglio, T De Palo, C Pecoraro, S Picca, S Testa, E Vidal, E Verrina	United Kingdom	M Sinha, and the staff of the UK Renal Registry
Lithuania	A Jankauskiene, B Pundziene		