

An update on the Registry- January 2021



Jérôme Harambat and Enrico Vidal

As members of the ESPN/ERA-EDTA Registry committee we would like to thank you for your participation and efforts to the Registry. Currently, 36 countries are participating in the Registry, providing information on nearly 24,000 patients who started KRT before the age of 20.

In 2020, two papers based on Registry data have been published, one has been accepted and another one has 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. In 2020, two fellows joined the Registry. Simeon Dupont from Hamburg, Germany, started a project on comorbidities in children commencing KRT. Evgenia Preka from Southampton, UK has started her part-time PhD trajectory at the Registry. Her current focus is on re-transplantation in adulthood after paediatric kidney transplantation.

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:

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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 KRT on an annual basis via the national renal registries in Europe. So far, data have been included from eleven subsequent years. Due to the process of obtaining signed Data Transfer Agreements with all national renal registries, last year's Annual Report only included limited information and we will show data for the years 2017 and 2018 in the current Annual Report.

In 2017 and 2018, the overall incidence were 4.4 and 4.9 per million age-related population (pmarp), respectively. The incidence ranged from 0.0, as no patients started KRT in that year, to 21.4 pmarp. The prevalence was 29.7 pmarp in 2017 and 30.1 pmarp in 2018. There was also a large variation in prevalence

rates across countries; it ranged from 8.0 to 91.4 pmarp. Five-year patient survival was 93.5% after start of KRT. Most patients died because of infections.

Two papers have been published in 2020.

Transplantation published our paper on post-transplant growth, showing no substantial improvement over the past 25 years. A paper on disparities in paediatric kidney transplantation has been published by Kidney International. This study revealed a large variation in kidney transplantation rates across European countries, which was strongly associated with country welfare,

whereas graft survival was rather similar.

A paper on 10 year trends in the epidemiology of European paediatric KRT was accepted for publication by Pediatric Nephrology and published online in January 2021. Furthermore, a revised version of our paper on kidney transplantation in small children and infants has been submitted to Transplantation.

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!

Table 1: Incident Patients

Incident paediatric patients accepted for kidney replacement therapy in 2017 and 2018 and general population characteristics of countries contributing data to the ESPN/ERA-EDTA Registry

Country	Total 2018 KRT patients		General Population 2018 Children		Total 2017 KRT patients		General Population 2017 Children	
	0-14 years		0-14 years		0-14 years		0-14 years	
	N	pmarp	N	percent	N	pmarp	N	Percent
Albania	1	2.0	500,186	17.9	11	21.4	514,530	17.9
Austria	5	3.9	1,273,002	14.4	8	6.3	1,263,740	14.4
Belarus	3	1.9	1,603,484	16.8	8	5.0	1,594,936	16.8
Bosnia and Herzegovina	1	1.8	543,719	15.4	2	3.7	543,719	15.4
Bulgaria	1	1.0	1,004,611	14.2	4	4.0	1,002,697	14.2
Cyprus	0	0.0	140,747	16.3	0	0.0	139,798	16.3
Czech Republic	12	7.1	1,681,869	15.7	8	4.8	1,658,975	15.7
Denmark	8	8.3	959,020	16.7	7	7.3	961,069	16.7
Estonia	0	0.0	216,324	16.3	1	4.7	214,417	16.3
Finland	7	7.9	886,329	16.2	11	12.3	892,302	16.2
France	74	6.1	12,092,930	18.2	82	6.7	12,162,436	18.2
Germany-CERTAIN*	9	0.8	11,231,286	13.4	5	0.5	11,110,163	13.4
Greece	8	5.2	1,541,871	14.4	5	3.2	1,550,669	14.4
Hungary	5	3.5	1,421,827	14.5	9	6.3	1,422,391	14.5
Iceland	0	0.0	67,613	19.5	1	14.9	67,111	19.5
Ireland	3	3.0	1,007,104	21.0	7	6.9	1,007,452	21.0
Italy	36	4.5	8,021,196	13.4	42	5.2	8,131,380	13.4
Latvia	2	6.6	305,186	15.7	0	0.0	304,438	15.7
Malta	0	0.0	66,866	14.0	1	15.2	65,656	14.0
Norway	6	6.4	936,946	17.8	5	5.3	938,322	17.8
Portugal	7	4.9	1,415,730	13.9	8	5.6	1,433,156	13.9
Republic of Serbia	7	7.0	1,000,598	14.4	2	2.0	1,008,736	14.4
Romania	23	7.5	3,047,361	15.6	14	4.6	3,054,752	15.6
Russia	105	4.5	23,383,808	16.3	95	4.1	23,383,808	16.3
Slovakia	4	4.7	853,871	15.5	2	2.4	844,965	15.5
Slovenia	1	3.2	312,192	15.0	3	9.7	309,635	15.0
Spain	49	7.0	6,954,342	15.0	52	7.4	6,991,873	15.0
Switzerland	3	2.3	1,283,746	15.0	6	4.7	1,269,055	15.0
the Netherlands	12	4.4	2,751,222	16.0	14	5.1	2,772,196	16.2
Turkey*	45	2.4	19,108,909	23.6	67	3.5	18,979,635	23.6
Ukraine	21	3.1	6,862,759	16.4	33	4.8	6,895,699	16.3
Total*	404	4.9	82,136,459	15.9	441	5.4	82,399,913	15.9

* Data from the German transplantation registry are based on 18 transplantation centres. In 2017, 117 patients and in 2018 133 patients under the age of 21 years were transplanted in Germany. The incidence in Turkey is an underestimation of the true incidence. Therefore, Germany and Turkey were excluded from the overall incidence.

Table 2: Treatment modality at start of KRT in 2017 and 2018

Treatment modality at day 1, among patients < 15 years of age starting KRT in 2017 and 2018. Patients from Germany and Turkey are excluded.

	2018			2017		
	N	Percent	Pmarp	N	Percent	Pmarp
HD at start	177	43.8	2.15	202	45.8	2.45
PD at start	153	37.9	1.86	159	36.1	1.93
Pre-emptive transplantation	72	17.8	0.88	78	17.7	0.95
Unknown	2	0.5	0.02	2	0.5	0.02

Table 3: PRD distribution at start of KRT in 2017 and 2018

Cause of kidney failure, among patients <15 years of age starting KRT in 2017 and 2018, according to new and old PRD coding. Patients from Germany and Turkey are excluded.

	2018						2017					
	N		Percent		Pmarp		N		Percent		Pmarp	
	New	Old	New	Old	New	Old	New	Old	New	Old	New	Old
CAKUT	162	135	40.1	33.4	1.97	1.64	169	124	38.3	28.1	2.05	1.50
Glomerulonephritis	73	64	18.1	15.8	0.89	0.78	71	66	16.1	15.0	0.86	0.80
Cystic kidney disease	52	58	12.9	14.4	0.63	0.71	53	64	12.0	14.5	0.64	0.78
Hereditary nephropathy	-	24	-	5.9	-	0.29	-	30	-	6.8	-	0.36
Metabolic and tubulointerstitial disorders	13	8	3.2	2.0	0.16	0.10	22	11	5.0	2.5	0.27	0.13
Toxic/ischemic renal failure	12	9	3.0	2.2	0.15	0.11	14	9	3.2	2.0	0.17	0.11
HUS	22	21	5.5	5.2	0.27	0.26	33	33	7.5	7.5	0.40	0.40
Vascular	2	2	0.5	0.5	0.02	0.02	7	6	1.6	1.4	0.08	0.07
Miscellaneous	66	56	16.3	13.9	0.80	0.68	69	67	15.6	15.2	0.84	0.81
Unknown	2	27	0.5	6.7	0.02	0.33	3	31	0.7	7.0	0.04	0.38

Table 4: eGFR at start of KRT in 2017 and 2018

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 2017 and 2018. Patients from Germany are excluded.

	2018		2017	
	N	Percent	N	Percent
eGFR<8 ml min ⁻¹ per 1.73 m ²	52	34.2	61	35.1
eGFR 8- 15 ml min ⁻¹ per 1.73 m ²	78	51.3	86	49.4
eGFR>15 ml min ⁻¹ per 1.73 m ²	22	14.5	27	15.5

Table 5: Prevalent patients

Prevalent paediatric patients on kidney replacement therapy on the 31st of December 2017 and 31st of December 2018.
Prevalent counts and prevalence per million age related population, by age groups.

Country	Total 2018		Age groups 2018			Total 2017		Age groups 2017		
	KRT patients		Infants	Children	Adolescents	KRT patients		Infants	Children	Adolescents
	0-14 years		0-4 years	5-9 years	10-14 years	0-14 years		0-4 years	5-9 years	10-14 years
	N	pmarp	pmarp	pmarp	pmarp	N	pmarp	Pmarp	pmarp	pmarp
Albania	9	18.0	12.6	18.3	22.5	16	31.1	36.5	18.3	37.6
Austria	53	41.6	30.1	31.0	64.0	53	41.9	32.9	36.2	56.7
Belarus	38	23.7	9.0	23.0	41.6	38	23.8	8.6	32.6	32.5
Bosnia and Herzegovina	5	9.2	0.0	11.3	15.6	8	14.7	0.0	17.0	26.0
Bulgaria	8	8.0	0.0	8.6	15.1	9	9.0	6.1	5.7	15.4
Cyprus	8	56.8	43.0	61.1	66.6	8	57.2	42.8	82.4	45.0
Czech Republic	50	29.7	14.2	13.8	63.0	44	26.5	7.2	15.3	60.5
Denmark	43	44.8	16.5	37.7	76.9	38	39.5	10.0	39.9	65.5
Estonia	1	4.6	0.0	0.0	14.1	2	9.3	0.0	13.1	14.7
Finland	81	91.4	80.6	80.8	112.0	79	88.5	81.3	77.5	106.7
France	489	40.4	18.8	38.4	62.0	492	40.5	19.8	39.4	60.5
Germany-CERTAIN*	279	24.8	8.2	25.7	41.4	270	24.3	8.2	25.4	39.9
Greece	43	27.9	12.8	18.7	50.1	44	28.4	2.1	29.4	50.6
Hungary	46	32.4	6.4	25.9	63.1	55	38.7	6.5	31.8	75.9
Iceland	4	59.2	47.1	0.0	132.5	4	59.6	46.8	42.2	90.9
Ireland	34	33.8	18.9	39.4	41.9	34	33.7	15.5	41.9	42.9
Italy*	91	11.3	9.6	8.7	15.3	98	12.1	11.8	11.1	13.3
Latvia	7	22.9	9.4	30.3	30.2	6	19.7	9.3	9.9	41.5
Malta	2	29.9	0.0	44.2	44.7	2	30.5	43.8	0.0	48.4
Norway	45	48.0	37.0	46.6	59.8	50	53.5	29.8	40.2	89.3
Portugal	73	51.6	23.4	42.1	83.8	74	51.6	21.1	43.2	84.6
Republic of Serbia	31	31.0	15.4	18.1	58.0	28	27.8	15.3	12.1	54.2
Romania	55	18.0	5.0	14.0	34.1	41	13.4	4.1	10.8	24.7
Russia	486	20.8	10.1	20.4	35.2	454	19.4	10.7	19.3	30.9
Slovakia	16	18.7	17.3	17.1	22.1	14	16.6	14.0	17.1	18.8
Slovenia	10	32.0	19.4	63.0	10.2	12	38.8	9.6	72.2	31.8
Spain	330	47.5	19.2	43.9	74.7	324	46.3	16.9	43.8	74.7
Switzerland	42	32.7	32.0	18.6	48.1	48	37.8	32.3	21.1	61.2
the Netherlands	112	40.7	15.0	53.1	52.0	122	44.0	13.8	59.2	56.5
Turkey*	346	18.1	9.1	17.3	28.2	385	20.3	11.3	16.9	33.2
Ukraine	109	15.8	10.0	9.8	30.5	108	15.7	6.7	10.5	33.6
Total*	2212	29.8	14.5	27.5	48.5	2207	29.7	14.0	28.3	48.4

* Data from the German transplantation registry are based on 18 transplantation centres. In 2017, 117 patients and in 2018 133 patients under the age of 21 years were transplanted in Germany. In Italy, deceased donor 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 kidney replacement therapy on the 31st of December 2017 and 31st of December 2018.

Prevalent counts and prevalence per million age related population, by age groups.

Country	Gender 2018		Treatment modality 2018			Gender 2017		Treatment modality 2017		
	0-14 years		0-14 years	0-14 years	0-14 years	0-14 year		0-14 years	0-14 years	0-14 years
	Male	Female	HD	PD	Transplantation	Male	Female	HD	PD	Transplantation
	pmarp	pmarp	pmarp	pmarp	pmarp	pmarp	pmarp	pmarp	pmarp	pmarp
Albania	19.4	16.5	6.0	2.0	4.0	33.8	28.2	19.4	1.9	3.9
Austria	53.4	29.1	2.4	2.4	36.9	56.9	26.0	4.0	4.7	33.2
Belarus	31.5	15.4	3.7	3.1	16.8	32.9	14.2	6.3	2.5	15.0
Bosnia and Herzegovina	7.2	11.3	7.4	0.0	1.8	21.5	7.6	9.2	0.0	5.5
Bulgaria	9.7	6.1	2.0	0.0	6.0	13.6	4.1	3.0	0.0	6.0
Cyprus	41.7	72.7	7.1	21.3	28.4	41.9	73.3	7.2	21.5	28.6
Czech Republic	33.6	25.6	4.2	4.8	20.8	34.1	18.6	3.6	2.4	20.5
Denmark	63.0	25.7	1.0	6.3	36.5	52.7	25.6	0.0	4.2	35.4
Estonia	0.0	9.5	0.0	0.0	4.6	9.1	9.6	0.0	0.0	9.3
Finland	112.5	69.3	1.1	1.1	89.1	107.4	68.8	3.4	3.4	81.8
France	47.4	33.1	6.8	4.7	29.1	47.3	33.3	7.2	3.9	28.9
Germany-CERTAIN*	30.0	19.4	-	-	24.7	29.6	18.7	-	-	24.0
Greece	32.8	21.3	9.7	12.3	5.2	32.6	22.5	9.7	10.3	8.4
Hungary	38.4	26.0	2.8	3.5	26.0	47.9	28.9	4.9	7.0	26.7
Iceland	115.5	0.0	0.0	14.8	44.4	116.7	0.0	0.0	14.9	44.7
Ireland	33.0	34.6	7.9	6.0	18.9	34.9	32.5	8.9	8.9	14.9
Italy*	13.8	8.7	4.7	4.6	2.0	13.1	10.9	4.8	5.8	1.5
Latvia	25.4	20.3	0.0	13.1	9.8	25.5	13.6	0.0	6.6	13.1
Malta	57.9	0.0	0.0	0.0	29.9	59.0	0.0	0.0	0.0	30.5
Norway	58.2	37.3	1.1	4.3	42.7	64.4	41.6	0.0	3.2	50.1
Portugal	66.3	36.1	3.5	13.4	34.6	66.8	35.7	2.1	11.2	37.7
Republic of Serbia	40.7	20.6	8.0	6.0	17.0	30.8	24.5	6.9	3.0	17.8
Romania	18.5	17.5	11.2	4.6	2.0	14.7	12.2	8.5	3.6	1.3
Russia	24.8	16.7	2.7	7.4	10.6	23.8	14.8	2.5	7.3	9.7
Slovakia	20.5	16.8	5.9	7.0	5.9	13.8	19.4	3.6	8.3	4.7
Slovenia	24.9	39.6	3.2	12.8	12.8	31.4	46.5	3.2	12.9	22.6
Spain	59.7	34.4	4.2	2.9	39.8	59.9	31.9	3.7	12.9	38.0
Switzerland	36.4	27.2	0.8	4.7	27.3	39.9	34.0	1.6	8.7	27.6
the Netherlands	49.7	31.3	1.8	3.3	36.7	51.4	36.2	2.2	1.1	40.8
Turkey*	18.0	18.2	2.8	7.7	7.6	20.9	19.6	3.6	9.4	7.3
Ukraine	19.1	15.2	3.6	2.6	9.6	17.2	15.8	4.5	3.0	8.1
Total*	36.2	24.1	4.3	5.3	20.3	36.0	23.4	4.4	4.9	20.0

* Data from the German transplantation registry are based on 18 transplantation centres. In 2017, 117 patients and in 2018 133 patients under the age of 21 years were transplanted in Germany. In Italy, deceased donor 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 6: Hypertension and height in children on KRT

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	49.4 (47.1-51.8)	30.0 (28.7-31.4)
Mean z-score systolic blood pressure	1.43 (1.36-1.51)	0.85 (0.81-0.89)
Mean z-score diastolic blood pressure	1.26 (1.20-1.31)	0.70 (0.67-0.74)
Height		
% of patients with height z-score < -2	46.8 (45.3-48.3)	36.5 (35.1-38.0)
Mean height z-score	-1.74 (-1.82; -1.65)	-1.68 (-1.73; -1.63)

Figure 1: Five-year patient survival

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

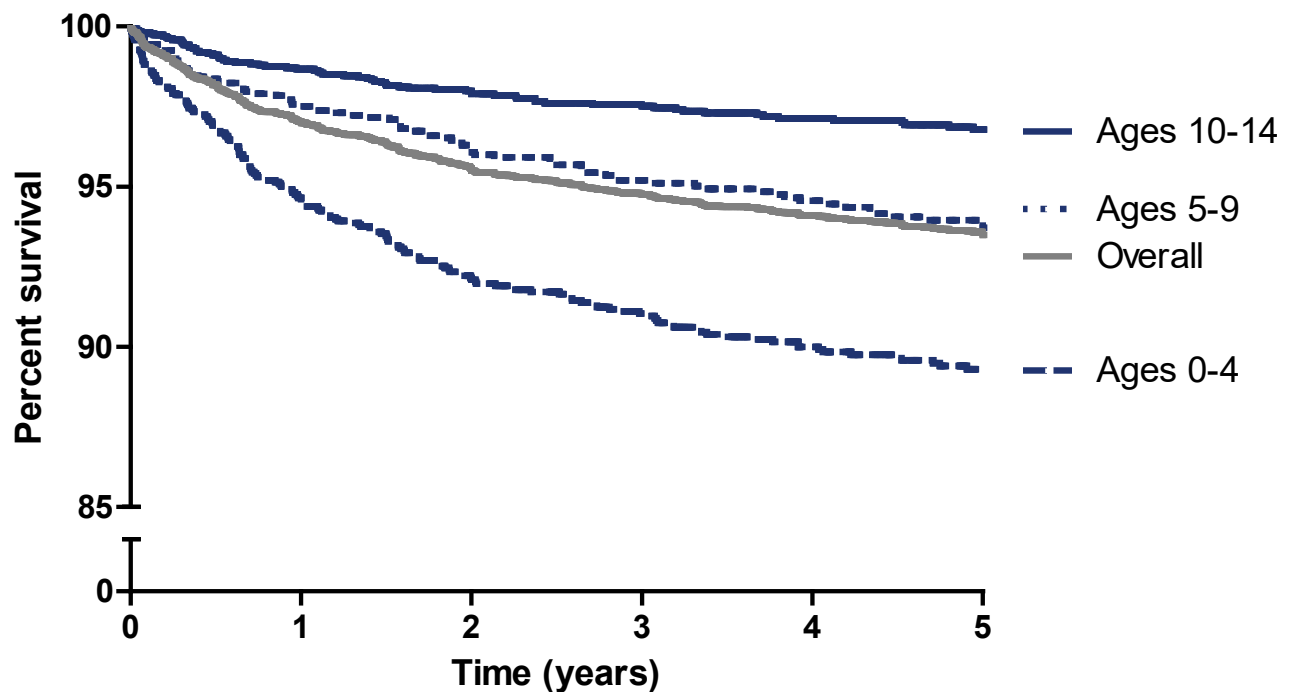


Table 7: Causes of Death

Causes of death according to the ERA-EDTS coding list. Incident RRT patients under the age of 15 starting KRT from 2007 onwards are included. Follow-up till 31st of December 2018.

Cause of death	Number of deaths	Percent
Myocardial ischemia and infarction	3	0.7
Cardiac failure	51	11.5
Cardiac arrest/sudden death other cause	71	16.0
Cerebro-vascular accident	28	6.3
Infection	94	21.2
Suicide/refusal or cessation of treatment	4	0.9
Treatment withdrawn	2	0.5
Malignant disease	14	3.2
Other identified cause of death	60	13.5
Cause of death uncertain/not determined	117	26.4

ESPN/ERA-EDTA Registry Scientific Committee

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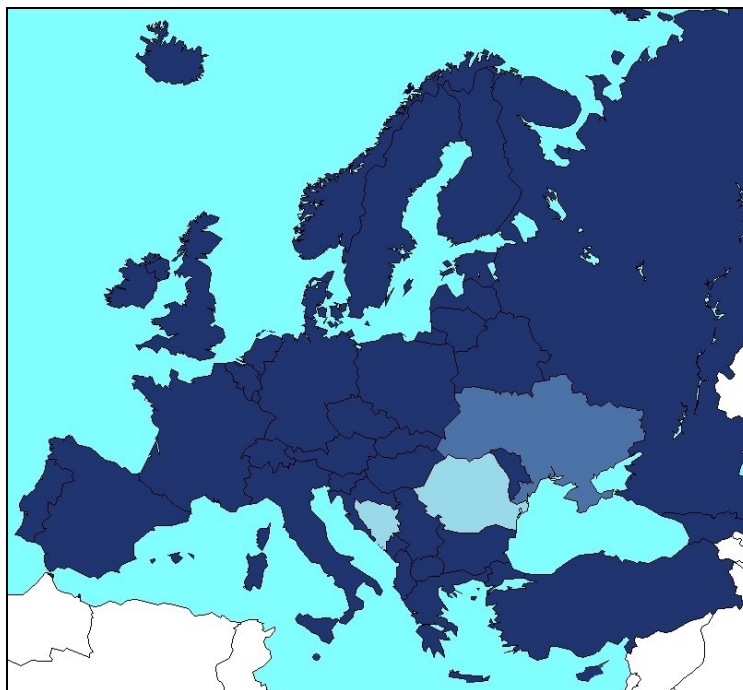
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Publication list 2020

1. Growth patterns after kidney transplantation in European children over the past 25 years: An ESPN/ERA-EDTA Registry Study. Bonthuis M, Groothoff JW, Ariceya G, Baiko S, Battelino N, Bjerre A, Cransberg K, Kolvek G, Maxwell H, Miteva P, Molchanova MS, Neuhaus TJ, Pape L, Reusz G, Rousset-Rouviere C, Sandes AR, Topaloglu R, van Dyck M, Ylinen E, Zagozdzon I, Jager KJ, Harambat J. *Transplantation* 2020 Jan;104(1):137-144

2. Results in the ESPN/ERA-EDTA Registry suggest disparities in access to kidney transplantation but little variation in graft survival of children across Europe. Bonthuis M, Cuperus L, Chesnaye NC, Akman S, Melgar AA, Baiko S, Bouts AH, Boyer O, Dimitrova K, Carmo CD, Grenda R, Heaf J, Jahnukainen T, Jankauskiene A, Kaltenegger L, Kostic M, Marks SD, Mitsioni A, Novljan G, Palsson R, Parvex P, Podracka L, Bjerre A, Seeman T, Slavicek J, Szabo T, Tönshoff B, Torress DD, van Hoeck KJ, Ladfors SW, Harambat J, Groothoff JW, Jager KJ. *Kidney Int* 2020 Aug;98(2):464-475



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

We sincerely thank the following countries and persons for their willingness to provide data to the Registry

Albania	D Shtiza	Latvia	A Popova, V Kuzema, H Čerņevskis,
Austria	F Engler, J Kerschbaum, G Mayer R Kramar	Lithuania	A Jankauskiene, S Rudaitis
Belarus	S Baiko, O Raikevich-Liachovskaya, A Dudarevich, I Sheuchuk	Malta	V Said-Conti
Belgium	K van Hoeck and the Centre contributors to the Belgian Registry Committee	Moldova	S Gatcan, O Berbeca, N Zaikova, N Revenco
Bosnia Herzegovina	D Pokrajac	Montenegro	S Pavičević
Bulgaria	D Roussinov	Norway	A Åsberg, AV Reisæter, A Bjerre
Croatia	D Milosevic, M Ban, J Slavicek, D Arapovic, S Abdovic	North Macedonia	E Sahpazova, N Abazi
Cyprus	A Elia	Poland	A Zurowska, I Zagodzdon
Czech Republic	T Seeman, K Vondrak	Portugal	C Mota, R Stone
Denmark	K Hommel	Romania	G Mircescu, L Garneata
Estonia	Ü Toots	Russia	EA Molchanova, EV Zakharova, AM Andrusev
Finland	J Helve, P Finne, P-H Groop	Serbia	M Kostić, B Spasojević, M Cvetković, I Gojković, D Paripović, G Miloševski-Lomić
France	C Couchoud, M Lassalle, E Berard	Slovakia	L Podracka, G Kolvek
Georgia	T Davitaia	Slovenia	N Battelino, G Novljan, J Buturovic-Ponikvar
Germany - CERTAIN	K Krupka, B Höcker, L Pape, B Tönshoff	Spain	A Alonso Melgar and the Spanish Paediatric Registry
Germany - KfH	K Rascher, E Nüsken, L Weber, G von Gersdorff, Jörg Dötsch, F Schaefer	Sweden	KG Prütz, M Stendahl, M Evans, S Schön M Segelmark, T Lundgren
Greece	N Afentakis, A Kapogiannis, A Mitsioni, N Printza	Switzerland	E Maurer, GF Laube, CE Kuehni, P Parvex, S Tschumi, L Mader
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Iceland	R Palsson, V Edvardsson	Turkey	S Bakkaloglu
Ireland	A Awan, T Raftery, C Sweeney, N Dolan	Ukraine	DD Ivanov, SP Fomina
Italy	B Gianoglio, I Guzzo, E La Porta, F Paglialonga, C Pecoraro, E Vidal, E Verrina	United Kingdom	L Plumb, F Braddon, A Casula, MD Sinha, H Maxwell