

An update on the Registry- February 2022



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As members of the ESPN/ERA Registry committee we would like to thank you again for your participation in and efforts to the Registry.

Currently, 35 countries are participating in the Registry, providing information on more than 24,000 patients who started KRT before the age of 20 years.

In 2021, three papers based on Registry data have been published 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 2021, two fellows joined the ESPN/ERA Registry. Henna Kaijansinkko a paediatric nephrologist from Helsinki, Finland, started a project on cancer as cause of ESKD. Evgenia Preka from, London, UK continued her part-time PhD trajectory at the Registry. She is currently working on two papers on re-transplantation in adulthood after

If you are also interested in performing a research project on the Registry or you would like to know more about participating in the ESPN/ERA 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 Registry collects data on KRT on an annual basis via national renal registries in Europe. So far, data have been included from thirteen subsequent years.

In 2019, the overall incidence was 5.0 per million age-related population (pmarp) and ranged from 0.0, as no patients started KRT in that year, to 8.6 pmarp. The prevalence was 35.5 pmarp and also showed a wide range from 5.5 to 89.0 pmarp. Five-year patient survival was 93.3% after the start of KRT and most patients died of infections.

Three papers have been published last year. Pediatric nephrology published two papers. The first one was our paper on 10 year trends in the epidemiology and outcomes of paediatric KRT in Europe, showing a stable incidence, but an increasing prevalence in the past 10 years. Five-year patient survival remained >93% and did not change over time. Secondly, Pediatric nephrology published an Educational review on growth, which was part of the Festschrift for Lesley Rees. We are very glad we could contribute to this collection.

A paper on the association between body weight and outcome in small children receiving a kidney transplant has been published online in Transplantation.

Another paper on comorbidities at start of KRT has been submitted to a scientific journal.

We are very proud about all these results, which would not have been possible without your great dedication 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 2019 and general population characteristics of countries contributing 2019 data to the ESPN/ERA Registry.

Country	Total		General Population Characteristics		
	KRT patients		Children	Total Population	Children
	0-14 years		0-14 years	0-99 years	0-14 years
	N	pmarp	N	N	percent
Albania	3	6.2	486,136	2,854,192	17.5
Austria	8	6.3	1,278,692	8,858,775	14.4
Belarus	5	3.1	1,604,711	9,465,675	17.0
Bosnia and Herzegovina	0	0.0	543,719	3,531,159	15.4
Bulgaria	3	3.0	1,003,551	6,975,759	14.3
Cyprus	1	7.1	141,793	881,950	16.2
Czech Republic	6	3.5	1,701,632	10,671,871	15.8
Denmark	6	6.3	955,294	5,814,425	16.6
Estonia	0	0.0	218,063	1,326,897	16.4
Finland	5	5.7	876,636	5,521,608	16.1
France	53	4.4	12,076,063	67,248,923	18.1
Georgia	4	5.3	749,720	3,726,549	20.1
Germany-CERTAIN*	6	0.5	11,341,037	83,092,963	13.5
Greece	2	1.3	1,532,298	10,721,584	14.4
Hungary	6	4.2	1,421,538	9,771,141	14.5
Iceland	0	0.0	68,018	360,562	19.2
Ireland	3	3.0	1,006,912	4,934,340	20.7
Latvia	1	3.3	305,134	1,913,821	15.8
Lithuania	2	4.7	422,300	2,794,138	15.1
Malta	0	0.0	68,330	504,061	13.8
North Macedonia	2	5.9	338,293	2,076,521	16.4
Norway	8	8.6	932,542	5,347,897	17.6
Poland	24	4.1	5,847,930	37,965,476	15.3
Portugal	9	6.4	1,402,276	10,286,263	13.8
Republic of Serbia	1	1.0	992,593	6,945,234	14.3
Romania	16	5.3	3,036,810	19,371,647	15.6
Russia	85	3.9	21,534,456	142,368,368	15.1
Slovakia	3	3.5	860,881	5,454,146	15.7
Slovenia	0	0.0	314,754	2,088,385	15.1
Spain	59	8.5	6,903,637	47,134,840	14.9
Sweden	10	5.5	1,827,275	10,278,887	17.8
the Netherlands	9	3.3	2,732,958	17,344,871	16.0
Turkey*	61	3.2	19,198,338	82,579,437	23.5
Ukraine	34	5.3	6,386,756	41,732,779	15.4
United Kingdom#	87	7.8	11,095,276	61,333,507	18.1
Total*	455	5.0	90,665,750	567,615,750	16.0

*Data from the German transplantation registry are based on 18 transplantation centres. In 2019, 130 patients under the age of 21 years were transplanted 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, and Turkey were excluded from the overall incidence.

#Does not include Scottish patients.

Table 2: Treatment modality at start of KRT in 2019

Treatment modality at day 1, among patients < 15 years of age starting KRT in 2019.
Patients from Germany, and Turkey are excluded.

	N	Percent	Pmarp
HD at start	190	41.8	2.10
PD at start	182	40.0	2.01
Pre-emptive transplantation	82	18.0	0.90
Unknown	1	0.2	0.01

Table 3: PRD distribution at start of KRT in 2019

Cause of renal failure, among patients < 15 years of age, starting KRT in 2019 according to new and old PRD coding.

	N		Percent		Pmarp	
	New	Old	New	Old	New	Old
CAKUT	185	133	40.7	29.2	2.04	1.47
Glomerulonephritis	81	75	17.8	16.4	0.89	0.83
Cystic kidney disease	44	64	9.7	14.1	0.49	0.71
Hereditary nephropathy	-	28	-	6.1	-	0.31
Metabolic and tubulointerstitial disorders	16	10	3.5	2.2	0.18	0.11
Toxic/ischemic renal failure	5	3	1.1	0.7	0.06	0.03
HUS	16	16	3.5	3.5	0.18	0.18
Vascular	4	4	0.9	0.9	0.04	0.04
Miscellaneous	78	58	17.1	12.7	0.86	0.64
Unknown	26	64	5.7	14.1	0.29	0.71

Table 4: eGFR at start of KRT

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 2019.

	N	Percent
eGFR<8 ml min ⁻¹ per 1.73 m ²	82	42.1
eGFR 8- 15 ml min ⁻¹ per 1.73 m ²	90	46.2
eGFR>15 ml min ⁻¹ per 1.73 m ²	23	11.8

Table 5: Prevalent Patients

Prevalent paediatric patients on kidney replacement therapy on the 31st of December 2019. Prevalent counts and prevalence per million age related population, by age groups.

Country	Total KRT		Age Groups		
	0-14 years		Infants	Children	Adolescents
	N	pmarp	0-4 years pmarp	5-9 years pmarp	10-14 years pmarp
Albania	9	18.5	13.2	12.2	29.3
Austria	48	37.5	23.0	26.2	63.8
Belarus	36	22.5	17.9	12.4	39.5
Bosnia and Herzegovina	3	5.5	0.0	11.3	5.2
Bulgaria	10	10.0	0.0	14.6	14.8
Cyprus	10	70.5	63.9	81.7	65.4
Czech Republic	45	26.4	5.3	21.1	53.0
Denmark	37	38.7	26.1	25.8	62.0
Estonia	2	9.2	0.0	13.6	13.6
Finland	78	89.0	72.6	97.5	94.4
France	483	40.0	16.9	40.2	60.2
Georgia	18	24.0	7.2	19.5	51.2
Germany-CERTAIN*	301	26.5	7.9	27.6	45.4
Greece	39	25.5	12.9	15.4	45.6
Hungary	53	37.3	14.9	26.2	68.6
Iceland	3	44.1	47.0	0.0	85.8
Ireland	11	10.9	6.4	5.7	20.4
Latvia	6	19.7	9.6	20.2	29.5
Lithuania	9	21.3	0.0	27.7	38.2
Malta	2	29.3	0.0	43.3	46.4
North Macedonia	10	29.6	9.1	8.6	71.2
Norway	45	48.3	37.6	44.1	62.0
Poland	221	37.8	21.9	29.0	62.2
Portugal	65	46.4	20.8	47.7	67.0
Republic of Serbia	28	28.2	9.3	18.2	55.9
Romania	59	19.4	6.0	11.3	39.6
Russia	521	24.2	10.4	23.5	41.6
Slovakia	17	19.7	13.7	17.2	28.9
Slovenia	10	31.8	19.7	54.3	19.5
Spain	340	49.2	18.6	46.1	77.0
Sweden	96	52.5	29.8	54.7	73.0
the Netherlands	118	43.2	9.3	49.2	68.1
Turkey*	378	19.7	9.4	19.3	30.4
Ukraine	119	18.6	8.3	15.3	30.5
United Kingdom#	668	60.2	25.9	59.2	94.8
Total*	3219	35.5	15.8	33.3	57.2

*Data from the German transplantation registry are based on 18 transplantation centres. In 2019, 130 patients under the age of 21 years were transplanted in Germany. These numbers are an underestimation of true incidence. The incidence in Turkey is an underestimation of the true incidence. Therefore, Germany, and Turkey were excluded from the overall incidence.

#Does not include Scottish patients.

Table 5: Prevalent Patients (continued)

Prevalent paediatric patients on kidney replacement therapy on the 31st of December 2019. 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	20.1	16.9	4.1	2.1	6.2
Austria	45.6	29.0	1.6	0.8	35.2
Belarus	29.1	15.4	2.5	5.0	15.0
Bosnia and Herzegovina	3.6	7.6	5.5	0.0	0.0
Bulgaria	9.7	10.3	2.0	0.0	8.0
Cyprus	69.0	72.1	7.1	28.2	35.3
Czech Republic	31.0	21.7	2.4	3.5	20.6
Denmark	57.1	19.3	3.1	5.2	30.4
Estonia	8.9	9.4	4.6	0.0	4.6
Finland	107.1	70.0	0.0	2.3	86.7
France	45.2	34.0	7.1	4.1	28.8
Georgia	30.7	16.7	9.3	8.0	6.7
Germany-CERTAIN*	31.6	21.2	-	-	26.3
Greece	33.0	16.1	9.8	11.7	3.9
Hungary	46.6	27.4	2.1	8.4	26.7
Iceland	85.9	0.0	0.0	14.7	29.4
Ireland	9.7	12.2	5.0	3.0	3.0
Latvia	25.4	13.5	0.0	13.1	6.6
Lithuania	27.7	14.6	2.4	0.0	18.9
Malta	56.6	0.0	0.0	0.0	29.3
North Macedonia	40.0	18.4	3.0	11.8	14.8
Norway	60.6	35.5	1.1	4.3	42.9
Poland	43.3	32.0	3.1	7.4	27.4
Portugal	55.8	36.4	2.1	14.3	30.0
Republic of Serbia	39.1	18.7	8.1	3.0	17.1
Romania	20.5	18.3	12.2	4.0	3.3
Russia	28.8	19.3	3.1	8.1	13.0
Slovakia	20.4	19.1	3.5	7.0	9.3
Slovenia	24.7	39.3	3.2	9.5	15.9
Spain	61.8	35.9	5.4	3.3	40.6
Sweden	61.7	42.8	2.2	4.9	45.4
the Netherlands	51.4	35.5	1.1	3.7	38.4
Turkey*	20.2	19.2	3.1	7.7	8.9
Ukraine	18.8	18.4	4.9	3.6	10.2
United Kingdom#	72.1	47.7	6.2	7.3	46.2
Total*	41.9	28.5	4.7	5.9	24.8

*Data from the German transplantation registry are based on 18 transplantation centres. In 2019, 130 patients under the age of 21 years were transplanted in Germany. These numbers are an underestimation of true incidence. The incidence in Turkey is an underestimation of the true incidence. Therefore, Germany, and Turkey were excluded from the overall incidence.

#Does not include data from Scottish patients.

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 (Bonthuis et al, PLoS ONE 7(8): e42506. doi:10.1371/journal.pone.0042506). Blood pressure z-score was calculated following the fourth report of the National High Blood Pressure Education Program (NHBPEP). Hypertension was defined as having a systolic or diastolic blood pressure z-score ≥ 1.64 ($\geq 95^{\text{th}}$ percentile) (Pediatrics 2004; 114: 555–576).

	Dialysis	Transplantation
Blood pressure		
% of patients with hypertension	47.6 (45.8-49.5)	29.1 (28.0-30.2)
Mean z-score systolic blood pressure	1.33 (1.27-1.38)	0.80 (0.77-0.83)
Mean z-score diastolic blood pressure	1.20 (1.16-1.25)	0.71 (0.68-0.73)
Height		
% of patients with height z-score < -2	50.3 (49.1-51.6)	40.2 (39.0-41.4)
Mean height z-score	-2.04 (-2.09; -1.99)	-1.80 (-1.84; -1.76)

Figure 1: Five-year patient survival

Incident KRT patients under the age of 15 starting KRT from 2007 onwards. Follow-up till 31st of December 2019.

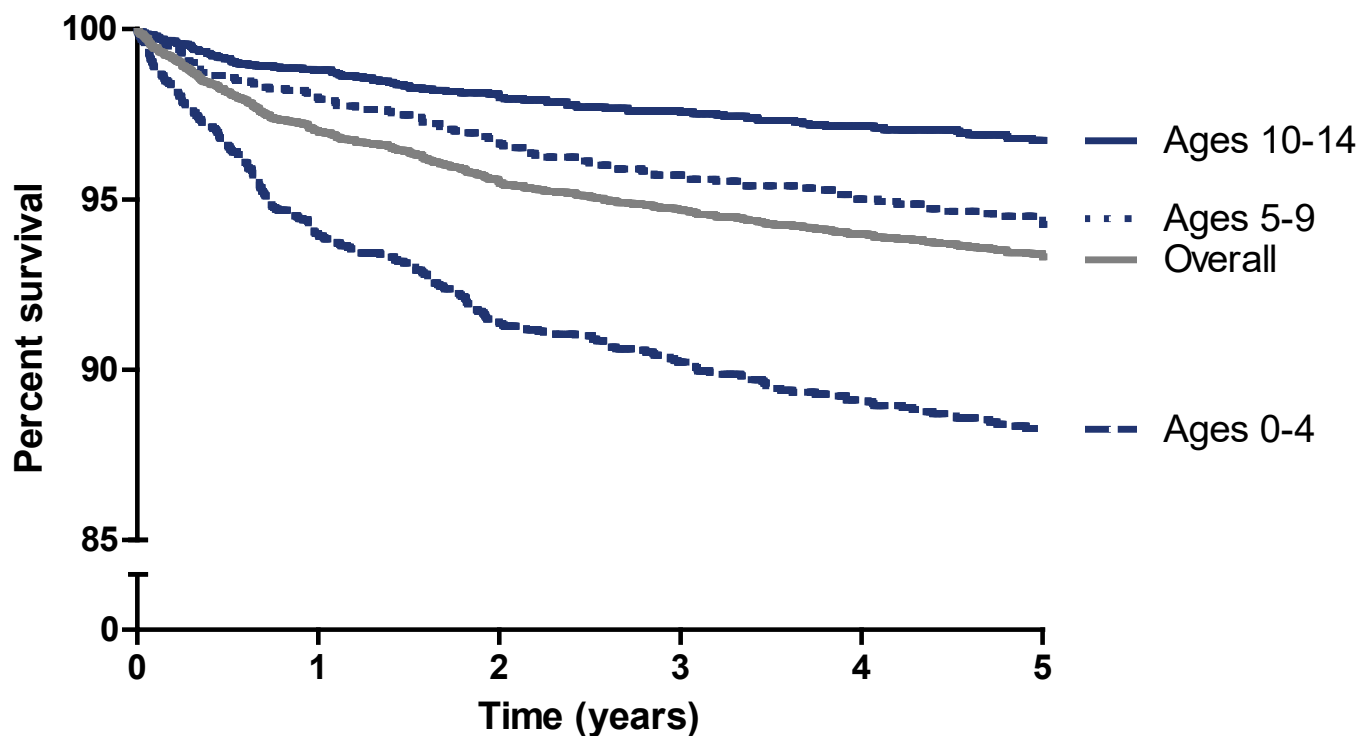


Table 7: Causes of Death

Causes of death according to the ERA coding list. Incident KRT patients under the age of 15 years starting KRT from 2007 onwards are included. Follow-up till 31st of December 2019.

Cause of death	Number of deaths	Percent
Myocardial ischemia and infarction	4	0.9
Cardiac failure	53	12.4
Cardiac arrest/sudden death other cause	62	14.5
Cerebro-vascular accident	36	8.4
Infection	116	27.1
Suicide/refusal or cessation of treatment	6	1.4
Treatment withdrawn	9	2.1
Malignant disease	2	0.5
Other identified cause of death	22	5.2
Cause of death uncertain/not determined	117	27.4

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Rezan Topaloglu, Turkey
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ESPN/ERA Registry

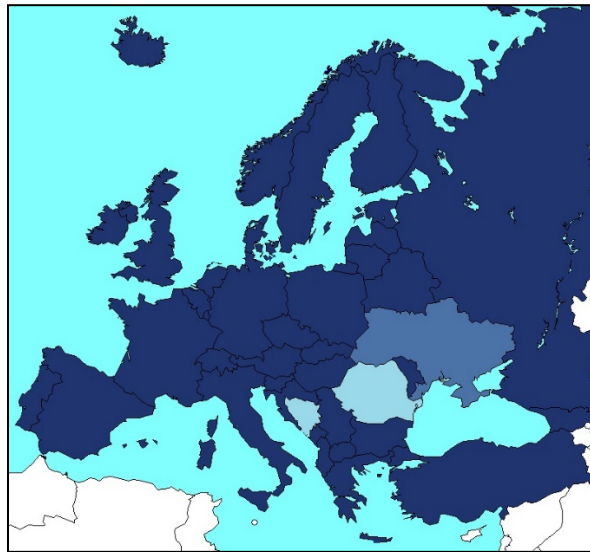
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Publication list 2021

1. Ten-year trends in epidemiology and outcomes of pediatric kidney replacement therapy in Europe: data from the ESPN/ERA-EDTA Registry. Bonthuis M, Vidal E, Bjerre A, Aydoğ Ö, Baiko S, Garneata L, Guzzo I, Heaf JG, Jahnukainen T, Lilien M, Mallett T, Mirescu G, Mochanova EA, Nüsken E, Rascher K, Roussinov D, Szczepanska M, Tsimaratos M, Varvara A, Verrina E, Veselinović B, Jager KJ, Harambat J. *Pediatr Nephrol* 2021 Aug;36(8):2337-2348

2. Growth in children on kidney replacement therapy: a review of data from patient registries. Bonthuis M, Harambat J, Jager KJ, Vidal E. *Pediatr Nephrol* 2018 Aug;36(8): 2563-2574.

3. Kidney transplantation in small children: Association between body weight and outcome- a report from the ESPN/ERA-EDTA Registry. Boehm M, Bonthuis M, Aufricht C, Battelino N, Bjerre A, Edvardsson VO, Herthelius M, Hubmann H, Jahnukainen T, de Jong H, Laube GF, Mattozzi F, Molchanova EA, Muñoz M, Noyan A, Pape L, Printza N, Reusz G, Roussey G, Rubik J, Spasojević-Dimitrijeva B, Seeman T, Ware N, Vidal E, Harambat J, Jager KJ, Groothoff J. *Transplantation* 2021 (Epub ahead of print).



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

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Bulgaria	D Roussinov	Montenegro	S Pavićević
Croatia	D Milosevic, M Ban, J Slavicek, D Arapovic, S Abdovic	North Macedonia	E Sahpazova, N Abazi
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