

An update on the Registry- February 2024



Enrico Vidal and Sevcan Bakkaloglu

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 28,000 patients who started KRT before the age of 20 years.

In 2022 and 2023, four 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 the past two years, three fellows joined the ESPN/ERA Registry. Simeon Dupont, a resident in paediatrics from Hamburg, Germany, worked on a project on comorbidities. Henna Kajjansinkko a paediatric nephrologist from Helsinki, Finland, started a project on cancer as cause of ESKD. Evgenia Preka from Paris, France continued her part-time PhD trajectory at the

Registry. She is currently finalizing two papers on re-transplantation in adulthood after paediatric kidney transplantation.

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 fifteen subsequent years. This Annual Report shows epidemiological data on paediatric KRT in Europe for the years 2020 and 2021

In 2020 and 2021, the overall incidence was 6.1 (range: 0.0 to 14.8) and 5.8 (range: 0.0 to 28.8) per million age-related population (pmarp), respectively. The prevalence was 39.3 (range: 9.0 to 88.9) pmarp in 2020 and 39.6 (range: 3.7 to 89.9) pmarp in 2021.

Five-year patient survival was 94.3% after the start of KRT and most patients for whom cause of death was reported, died of infections.

Four papers have been published during the past two years. Transplantation published our paper on the association between body weight and outcomes after kidney transplantation in young children.

Clinical Kidney Journal published two papers. The first one was our paper on comorbidities at start of KRT. Secondly, CKJ published the results from a survey on existing European paediatric CKD registries. Eight CKD registries have been identified which form the basis to establish an ESPN CKD registry linked to the ESPN/ERA Registry and subsequently linking it to the adult ERA Registry to follow CKD disease progression from childhood into adulthood.

Furthermore, a paper on anthropometry and clinical outcomes has been published in Pediatric Nephrology. Six more papers are currently in preparation and many more are planned.

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 2020 and 2021 and general population characteristics of countries contributing data to the ESPN/ERA Registry

	KRT patients 2021 0-14 years		General Population 2021 0-14 years		KRT patients 2020 0-14 years		General Population 2020 0-14 years	
	N	pmarp	N	percent	N	pmarp	N	Percent
Albania	1	2.1	473,107	16.7	7	14.8	473,107	16.7
Austria	4	3.1	1,285,488	14.4	6	4.7	1,283,060	14.4
Belarus	6	3.8	1,566,984	16.9	9	5.7	1,586,320	17.0
Bosnia and Herzegovina	0	0.0	543,719	15.4	3	5.5	543,719	15.4
Bulgaria	4	4.0	996,039	14.5	3	3.0	1,000,636	14.4
Croatia	1	1.8	563,549	14.3	2	3.5	578,179	14.3
Cyprus	0	0.0	144,493	16.0	0	0.0	143,043	16.0
Czech Republic	6	3.5	1,706,574	16.1	4	2.3	1,714,971	16.0
Denmark	4	4.2	947,308	16.2	4	4.2	950,951	16.3
Estonia	1	4.6	218,135	16.4	1	4.6	218,587	16.4
Finland	10	11.7	856,328	15.5	8	9.2	865,948	15.7
France	64	5.4	11,916,853	17.6	73	6.1	11,997,670	17.8
Georgia	2	2.6	769,878	20.6	2	2.6	759,018	20.4
Germany-CERTAIN*	7	0.6	11,542,369	13.9	8	0.7	11,434,529	13.7
Greece	5	3.4	1,469,861	13.9	5	3.3	1,519,128	14.2
Hungary	9	6.4	1,413,701	14.6	13	9.2	1,419,285	14.6
Iceland	2	28.8	69,396	18.6	1	14.6	68,604	18.6
Ireland	2	2.0	998,466	19.8	2	2.0	1,003,240	20.1
Latvia	1	3.3	301,484	16.0	1	3.3	304,083	16.0
Lithuania	6	14.3	419,877	15.0	5	11.8	422,556	15.0
Malta	0	0.0	69,647	13.4	0	0.0	69,235	13.4
North Macedonia	0	0.0	323,124	16.5	4	11.9	335,002	16.2
Norway	5	5.4	918,788	17.0	8	8.6	925,860	17.2
Poland	34	5.8	5,835,252	15.5	28	4.8	5,859,566	15.5
Portugal	12	8.9	1,353,756	13.1	7	5.0	1,389,806	13.5
Republic of Serbia	9	9.2	977,123	14.3	4	4.1	984,658	14.3
Romania	17	5.6	3,057,983	16.0	11	3.6	3,029,159	16.0
Slovakia	4	4.6	870,544	16.0	5	5.8	866,007	15.9
Slovenia	-	-	-	-	4	12.6	316,767	15.1
Spain	49	7.3	6,693,626	14.1	49	7.2	6,818,235	14.4
Sweden	10	5.4	1,838,451	17.7	15	8.2	1,836,309	17.7
the Netherlands	16	5.9	2,712,096	15.5	16	5.9	2,718,915	15.5
Turkey*	45	2.4	19,140,291	23.0	40	2.1	19,140,291	23.0
Ukraine	25	4.1	6,119,886	14.9	29	4.6	6,279,769	15.2
United Kingdom#	90	7.8	11,549,049	17.2	97	8.1	11,974,857	17.2
Total*	399	5.8	68,980,565	16.6	426	6.1	70,256,250	16.8

* Data from the German transplantation registry are based on 18 transplantation centres. In 2020, 98 patients and in 2021, 116 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. #Does not include Scottish patients.

Table 2: Treatment modality at start of KRT in 2020 and 2021

Treatment modality at day 1, among patients < 15 years of age starting KRT in 2020 and 2021. Patients from Germany and Turkey are excluded.

	2021			2020		
	N	Percent	Pmarp	N	Percent	Pmarp
HD at start	148	37.1	2.15	180	42.2	2.56
PD at start	171	42.9	2.48	170	39.9	2.42
Pre-emptive transplantation	78	19.5	1.13	74	17.4	1.05
Unknown	2	0.5	0.03	2	0.5	0.03

Table 3: PRD distribution at start of KRT in 2020 and 2021

Cause of kidney failure, among patients <15 years of age starting KRT in 2020 and 2021, according to new and old PRD coding. Patients from Germany and Turkey are excluded.

	2021						2020					
	N		Percent		Pmarp		N		Percent		Pmarp	
	New	Old	New	Old	New	Old	New	Old	New	Old	New	Old
CAKUT	125	116	31.3	29.1	1.81	1.68	129	129	30.3	30.3	1.84	1.84
Glomerulonephritis	53	49	13.3	12.3	0.77	0.71	72	67	16.9	15.7	1.02	0.95
Cystic kidney disease	61	61	15.3	15.3	0.88	0.88	63	63	14.8	14.8	0.90	0.90
Hereditary nephropathy	-	30	-	7.5	-	0.43	-	24	-	5.6	-	0.34
Metabolic and tubulointerstitial disorders	18	10	4.5	2.5	0.26	0.14	19	10	4.5	2.3	0.27	0.14
Toxic/ischemic renal failure	5	4	1.3	1.0	0.07	0.06	7	4	1.6	0.9	0.10	0.06
HUS	15	15	3.8	3.8	0.22	0.22	26	25	6.1	5.9	0.37	0.36
Vascular	4	4	1.0	1.0	0.06	0.06	4	4	0.9	0.9	0.06	0.06
Miscellaneous	115	36	28.8	9.0	1.67	0.52	106	31	24.9	7.3	1.51	0.44
Unknown	3	74	0.8	18.5	0.04	1.07	0	69	0.0	16.2	0.00	0.98

Table 4: eGFR at start of KRT in 2020 and 2021

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 2020 and 2021. Patients from Germany are excluded.

	2021		2020	
	N	Percent	N	Percent
eGFR<8 ml min ⁻¹ per 1.73 m ²	61	44.5	69	42.6
eGFR 8- 15 ml min ⁻¹ per 1.73 m ²	61	44.5	77	47.5
eGFR>15 ml min ⁻¹ per 1.73 m ²	15	11.0	16	9.9

Table 5: Prevalent patients

Prevalent paediatric patients on kidney replacement therapy on the 31st of December 2020 and 31st of December 2021. Prevalent counts and prevalence per million age related population, by age groups.

Country	Total 2021					Total 2020				
	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	14	29.6	20.6	30.7	36.5	15	31.7	27.4	30.7	36.5
Austria	53	41.2	20.7	44.4	59.0	53	41.3	27.5	30.6	66.4
Belarus	40	25.5	24.7	10.2	43.1	39	24.6	22.8	12.1	40.0
Bosnia and Herzegovina	2	3.7	5.7	0.0	5.2	5	9.2	5.7	5.7	15.6
Bulgaria	15	15.1	3.2	11.9	28.7	11	11.0	3.2	14.8	14.5
Croatia	28	49.7	16.8	48.4	80.4	29	50.2	27.5	51.6	69.2
Cyprus	9	62.3	0.0	61.5	125.6	9	62.9	21.1	61.5	106.7
Czech Republic	35	20.5	7.1	19.8	34.0	36	21.0	3.5	19.6	39.2
Denmark	36	38.0	25.8	19.9	65.5	37	38.9	22.7	29.7	62.0
Estonia	4	18.3	0.0	14.0	39.1	3	13.7	0.0	27.7	13.2
Finland	77	89.9	73.4	104.2	89.3	77	88.9	63.6	105.4	93.3
France	487	40.9	16.4	43.5	59.0	487	40.6	17.2	42.0	59.3
Georgia	18	23.4	3.9	11.2	56.5	19	25.0	7.5	15.3	56.4
Germany-CERTAIN*	284	24.6	5.8	29.7	39.4	300	26.2	7.8	29.3	42.8
Greece	35	23.8	11.4	12.5	43.8	38	25.0	13.1	9.9	48.6
Hungary	53	37.5	27.7	26.0	58.0	53	38.0	32.0	21.9	58.8
Iceland	4	57.6	135.0	0.0	40.8	2	29.2	46.3	0.0	41.7
Ireland	11	11.0	9.9	11.9	11.1	9	9.0	6.5	5.8	14.2
Latvia	8	26.5	10.4	28.7	39.7	7	23.0	9.9	29.6	29.4
Lithuania	16	38.1	14.9	20.6	78.4	12	28.4	7.0	27.5	52.1
Malta	2	28.7	0.0	41.7	44.8	2	28.9	0.0	42.4	45.5
North Macedonia	11	34.0	19.8	17.9	63.6	12	35.8	28.3	8.7	70.4
Norway	49	53.3	21.3	58.2	76.2	50	54.0	24.4	67.1	67.4
Poland	229	39.2	17.0	35.7	62.9	229	39.1	23.5	32.2	60.3
Portugal	70	51.7	19.0	43.4	87.0	67	48.2	20.6	44.4	75.5
Republic of Serbia	29	29.7	6.3	33.6	48.1	24	24.4	3.1	24.3	44.6
Romania	55	18.0	6.0	13.1	33.5	51	16.8	4.0	10.4	34.9
Slovakia	18	20.7	10.2	17.2	35.2	21	24.2	13.6	17.2	42.6
Slovenia	-	-	-	-	-	15	47.4	60.0	63.9	18.7
Spain	335	50.0	20.1	37.4	83.7	343	50.3	16.8	46.3	80.0
Sweden	93	50.6	25.3	54.7	70.4	97	52.8	31.8	51.4	74.7
the Netherlands	123	45.4	12.8	31.2	88.1	120	44.1	10.5	43.1	75.5
Turkey*	375	19.6	7.4	21.9	29.2	388	20.3	9.0	20.5	31.0
Ukraine	125	20.2	7.0	19.8	30.0	130	20.7	9.5	17.8	31.8
United Kingdom#	645	55.8	22.9	48.0	92.7	656	54.8	22.5	51.8	88.0
Total*	2729	39.6	17.2	35.1	63.0	2759	39.3	18.0	36.3	61.1

* Data from the German transplantation registry are based on 18 transplantation centres. In 2020, 98 patients and in 2021, 116 patients under the age of 21 years were transplanted in Germany. The prevalence in Turkey is an underestimation of the true prevalence. Therefore, Germany and Turkey were excluded from the overall prevalence. #Does not include Scottish patients.

Table 5: Prevalent patients (continued)

Prevalent paediatric patients on kidney replacement therapy on the 31st of December 2020 and 31st of December 2021.
Prevalent counts and prevalence per million age related population, by age groups.

Country	Gender 2021		Treatment modality 2021			Gender 2020		Treatment modality 2020		
	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	28.9	30.3	14.8	2.1	8.5	28.9	34.6	14.8	2.1	8.5
Austria	49.9	32.0	0.8	1.6	38.9	50.0	32.1	2.3	2.3	36.6
Belarus	34.8	15.7	1.3	6.4	17.9	31.9	16.8	2.5	6.9	15.1
Bosnia and Herzegovina	3.6	3.8	3.7	0.0	0.0	7.2	11.3	9.2	0.0	0.0
Bulgaria	19.5	10.3	1.0	2.0	12.0	13.6	8.2	2.0	1.0	8.0
Croatia	51.8	47.5	7.1	31.9	10.6	53.8	46.3	5.2	34.6	10.4
Cyprus	53.8	71.3	6.9	20.8	34.6	54.6	71.7	7.0	21.0	35.0
Czech Republic	25.2	15.6	1.2	5.9	13.5	25.0	16.7	1.7	3.5	15.7
Denmark	55.5	19.5	0.0	2.1	35.9	55.3	21.6	1.1	3.2	34.7
Estonia	17.9	18.8	4.6	0.0	13.8	8.9	18.8	0.0	4.6	9.1
Finland	114.2	64.5	1.2	0.0	88.8	108.4	68.5	1.2	0.0	87.8
France	46.9	34.5	6.9	3.8	30.2	46.2	34.8	6.9	3.7	29.7
Georgia	23.2	24.5	6.5	10.4	6.5	25.3	24.7	7.9	9.2	6.6
Germany – CERTAIN*	30.5	18.3	0.0	0.0	24.3	32.9	19.2	0.0	0.0	25.7
Greece	29.1	18.2	6.8	6.1	10.9	32.0	17.6	7.2	7.9	9.9
Hungary	45.5	29.1	5.0	9.2	23.3	48.0	27.5	4.9	10.6	21.8
Iceland	84.0	29.7	14.4	14.4	28.8	56.7	0.0	0.0	0.0	29.2
Ireland	13.7	8.2	3.0	5.0	3.0	9.7	8.2	2.0	4.0	3.0
Latvia	25.7	27.4	3.3	13.3	10.0	19.1	27.1	3.3	13.2	6.6
Lithuania	55.7	19.6	2.4	11.9	23.8	41.5	14.6	7.1	4.7	16.6
Malta	55.4	0.0	0.0	0.0	28.7	55.7	0.0	0.0	0.0	28.9
North Macedonia	41.9	25.6	3.1	9.3	21.7	46.2	24.7	3.0	11.9	20.9
Norway	67.8	38.0	0.0	4.4	47.9	65.2	42.2	3.2	3.2	47.5
Poland	48.7	29.2	5.1	7.2	26.6	46.5	31.2	4.6	8.0	26.5
Portugal	63.5	39.3	4.4	11.8	34.7	60.6	35.3	3.6	13.0	30.9
Republic of Serbia	41.7	16.9	3.1	12.3	13.3	37.4	10.5	8.1	4.1	12.2
Romania	22.3	13.5	11.4	2.6	3.9	17.4	16.3	10.2	2.6	4.0
Slovakia	22.4	18.8	4.6	11.5	4.6	27.0	21.3	4.6	11.5	8.1
Slovenia	-	-	-	-	-	49.0	45.6	9.5	22.1	15.8
Spain	62.6	36.7	4.0	3.6	42.3	64.6	35.1	3.7	4.0	42.5
Sweden	56.0	44.8	2.7	3.8	44.1	61.4	43.7	2.7	5.4	44.7
The Netherlands	53.3	37.1	3.7	4.1	37.6	53.8	33.9	2.6	3.7	37.9
Turkey*	20.6	18.8	2.4	8.0	9.2	21.9	18.6	3.2	8.2	8.9
Ukraine	20.9	19.9	4.2	4.1	12.3	20.7	20.7	4.3	5.4	11.0
United Kingdom#	68.0	43.1	5.9	7.5	42.4	65.3	43.7	6.3	7.5	40.8
Total*	47.6	31.2	5.0	5.6	28.8	46.7	31.5	5.2	5.8	28.1

* Data from the German transplantation registry are based on 18 transplantation centres. In 2020, 98 patients and in 2021, 116 patients under the age of 21 years were transplanted in Germany. The prevalence in Turkey is an underestimation of the true prevalence. Therefore, Germany and Turkey were excluded from the overall prevalence. #Does not include Scottish patients.

Table 6: Hypertension and height in children on KRT

Height z-score based on recent national reference charts, or, if unavailable, on 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	45.5 (43.9-47.1)	27.5 (26.5-28.5)
Mean z-score systolic blood pressure	1.28 (1.23-1.33)	0.80 (0.77-0.83)
Mean z-score diastolic blood pressure	1.15 (1.11-1.19)	0.72 (0.69-0.75)
Height		
% of patients with height z-score < -2	49.0 (47.8-50.3)	37.8 (36.6-38.9)
Mean height z-score	-2.04 (-2.09;-2.00)	-1.70 (-1.74;-1.66)

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 2021.

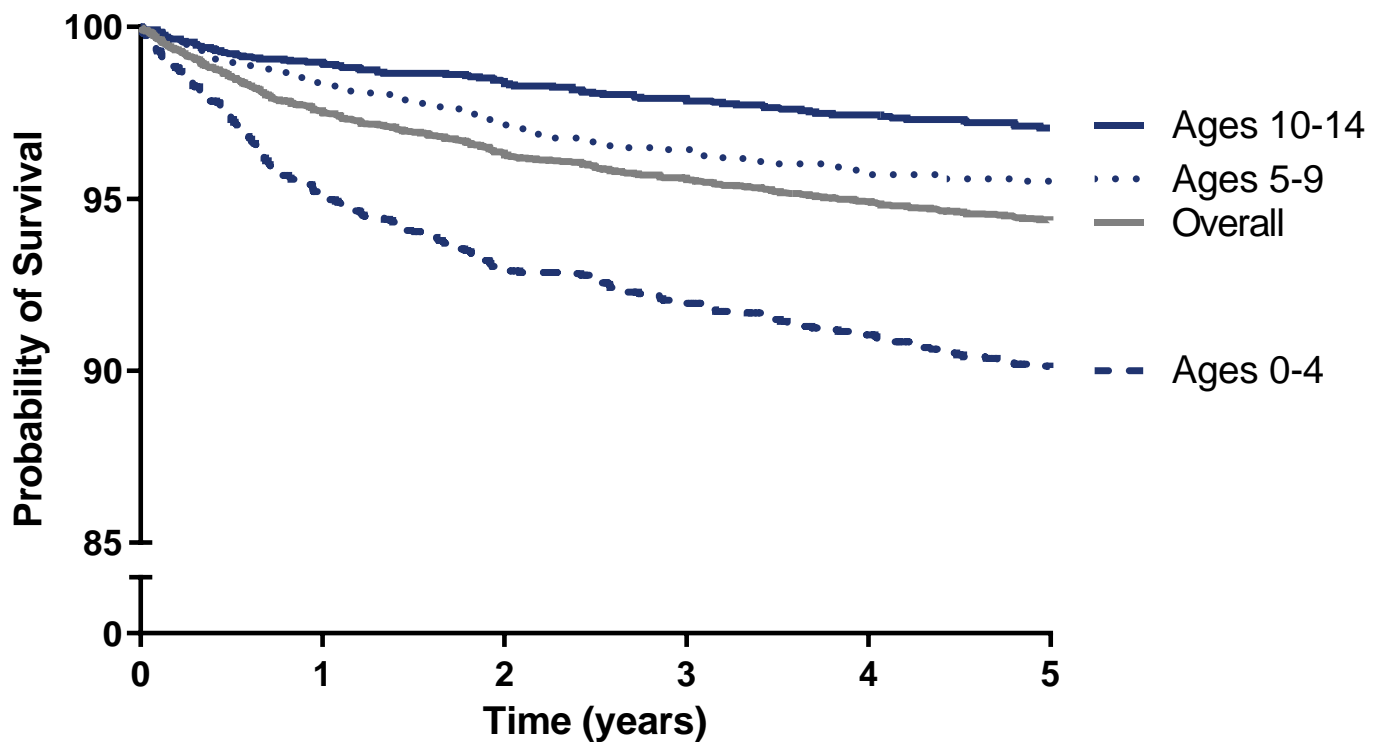


Table 7: Causes of Death

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 2021.

Cause of death	Number of deaths	Percent
Myocardial ischemia and infarction	5	0.9
Cardiac failure	42	7.4
Cardiac arrest/sudden death other cause	44	7.8
Cerebro-vascular accident	21	3.7
Infection	123	21.8
Suicide/refusal or cessation of treatment	3	0.5
Treatment withdrawn	16	2.8
Cachexia	1	0.2
Malignant disease	29	5.1
Other identified cause of death	100	17.7
Cause of death uncertain/not determined	181	32.0

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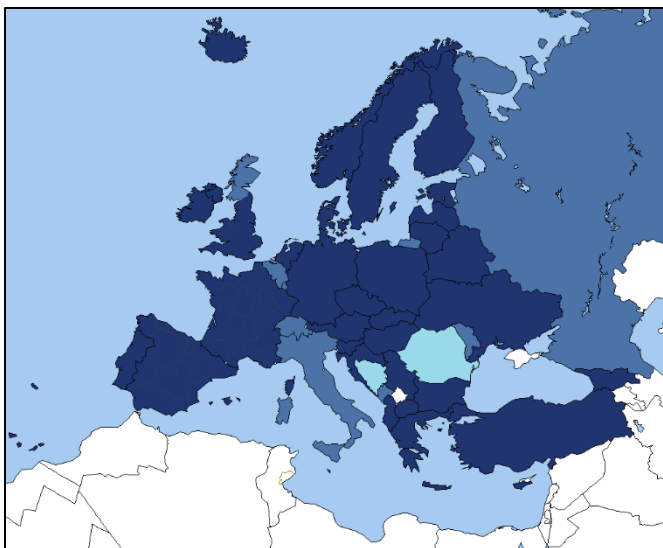
Publication list 2022 and 2023

1. 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, Spasojevic-Dimitrijeva B, Seeman T, Ware N, Vidal E, Harambat J, Jager KJ, Groothoff J. *Transplantation*. 2022 Mar 1;106(3):607-614

2. Disparities in treatment and outcome of kidney replacement therapy in children with comorbidities: an ESPN/ERA Registry study. Schild R, Dupont S, Harambat J, Vidal E, Balat A, Bereczki C, Bienias B, Brandström P, Broux F, Consolo S, Gojkovic I, Groothoff JW, Hommel K, Hubmann H, Braddon FEM, Pankratenko TE, Papachristou F, Plumb LA, Podracka L, Prokurat S, Bjerre A, Cordinhã C, Tainio J, Shkurti E, Spartà G, Vondrak K, Jager KJ, Oh J, Bonthuis M. *Clin Kidney J*. 2023 Jan 12;16(4):745-755

3. Associations of longitudinal height and weight with clinical outcomes in pediatric kidney replacement therapy: results from the ESPN/ERA Registry. Bonthuis M, Bakkaloglu SA, Vidal E, Baiko S, Braddon F, Errichiello C, Francisco T, Haffner D, Lahoche A, Leszczynska B, Masalkiene J, Stojanovic J, Molchanova MS, Reusz G, Barba AR, Rosales A, Tegeltija S, Ylinen E, Zlatanova G, Harambat J, Jager KJ. *Pediatr Nephrol*. 2023 Oct;38(10):3435-3443.

4. European chronic kidney disease registries for children not on kidney replacement therapy: tools for improving health systems and patient-centred outcomes. Bakkaloglu SA, Vidal E, Bonthuis M, Neto G, Paripovic D, Asberg A, Hijosa MM, Vondrak K, Jankauskiene A, Roussonov D, Awan, A, Jager KJ. *Clin Kidney J*. 2023 Sep;16(11):1980-1985.



Provided extended data to the
ESPN/ERA Registry in 2023

Provided data to the
ESPN/ERA Registry before 2023

Provided data via
the ERA Registry

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