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ESPN/ERA-EDTA Registry

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An update on the Registry- January 2020

Jérôme Harambat and Enrico Vidal

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

An important part of last year's Registry activities consisted of arranging Data Transfer Agreements (DTAs). For 28 countries the DTAs are signed and they are pending for the others. Because of this process, this Annual Report contains only limited information on a selected number of countries. Next time we aim to publish an extensive Annual Report including data of all participating countries for the years 2017 and 2018.

In 2019, Evgenia Preka, a paediatric nephrologist from the United Kingdom has started her (part-time) PhD project at the ESPN/ERA-EDTA Registry, which she will perform besides her clinical work. Her current work focusses on kidney re-transplantation of patients who received their first transplant during childhood.

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 the Registry Coordinator (Marjolein Bonthuis: m.bonthuis@amsterdamumc.nl).
Funding possibilities are available from the ESPN or the ERA-EDTA

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 eleven subsequent years.

Four papers and a Letter to the Editor have been accepted and published during the previous months.

Pediatric Nephrology published our paper on vascular access and the association with the subsequent access to transplantation. Showing that a catheter remains the most frequent type of vascular access in children commencing HD. Overall likelihood of transplantation was similar among patients with a catheter or a fistula, but patients with a fistula were less likely to receive a kidney from a living donor.

Furthermore, our paper on longitudinal growth after transplantation was published by *Transplantation*. In this paper we report that growth retardation still exists in nearly half of the transplant recipients and there was no improvement over the past 25 years.

A paper on eGFR at dialysis initiation, published by *Nephrol Dial Transplant*, showed no benefit of starting dialysis early in children with end-stage kidney disease.
Furthermore, *J Am Soc Nephrol* published our Letter to the Editor on this topic. With this letter we aim to raise awareness among clinicians that eGFR should not be the only criterion for the decision to initiate dialysis in children and decisions should be individualized instead.

A paper on clinical practice recommendations for growth hormone therapy in paediatric CKD was published in *Nat Rev Nephrol*, which is a collaborative project with the ESPN Working Groups on CKD-MBD, Dialysis and Transplantation.

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

Table 1: Incident patients

Incident paediatric patients accepted for renal replacement therapy in 2017 and general population characteristics of countries contributing 2017 data to the ESPN/ERA-EDTA Registry.
Countries that did not sign a Data Transfer Agreement are excluded from the analyses.

Country	Total RRT patients 0-14 years		General Population Characteristics		
			Children 0-14 years	Total Population 0-99 years	Children 0-14 years
	N	pmarp	N	N	percent
Albania	11	21.4	514,530	2,873,457	17.9
Austria	7	5.5	1,263,740	8,772,865	14.4
Belarus	8	5.0	1,594,936	9,491,823	16.8
Bosnia and Herzegovina	2	3.7	543,719	3,531,159	15.4
Bulgaria	4	4.0	1,002,697	7,075,945	14.2
Cyprus	0	0.0	139,798	859,517	16.3
Czech Republic	8	4.8	1,658,975	10,594,435	15.7
Denmark	7	7.3	961,069	5,764,981	16.7
Estonia	1	4.7	214,417	1,317,384	16.3
Finland	11	12.3	892,302	5,508,214	16.2
France	79	6.5	12,162,436	66,865,143	18.2
Germany-CERTAIN*	3	0.3	11,110,163	82,657,001	13.4
Greece	5	3.2	1,550,669	10,754,679	14.4
Iceland	1	14.9	67,111	343,400	19.5
Ireland	17	16.9	1,008,455	4,784,383	21.1
Italy	35	4.3	8,131,380	60,536,709	13.4
Latvia	0	0.0	304,438	1,942,246	15.7
Norway	5	5.3	938,322	5,276,969	17.8
Romania	13	4.3	3,054,752	19,587,491	15.6
Russia	80	3.9	21,534,456	142,368,368	15.1
Serbia	2	2.0	1,008,736	7,020,859	14.4
Slovakia	2	2.4	844,965	5,439,232	15.5
Slovenia	3	9.7	309,635	2,066,387	15.0
Spain	50	7.2	6,991,873	46,592,742	15.0
Turkey	58	3.1	18,979,635	80,312,698	23.6
Ukraine	32	4.9	6,530,490	42,216,766	15.5

* In 2017, 117 patients under the age of 21 years were transplanted in 18 transplantation centres in Germany.

Table 2: Prevalent Patients

Prevalent paediatric patients on renal replacement therapy on the 31st of December 2017.
Prevalent counts and prevalence per million age related population, by age groups.
Countries that did not sign a Data Transfer Agreement are excluded from the analyses.

Country	Total RRT 0-14 years		Age Groups		
	N	pmarp	Infants 0-4 years pmarp	Children 5-9 years pmarp	Adolescents 10-14 years pmarp
Albania	15	29.2	42.6	12.2	32.3
Austria	51	40.4	30.5	38.6	52.0
Belarus	38	23.8	8.6	32.6	32.5
Bosnia and Herzegovina	10	18.4	11.5	17.0	26.0
Bulgaria	10	10.0	9.1	5.7	15.4
Cyprus	8	57.2	42.8	82.4	45.0
Czech Republic	44	26.5	9.0	15.3	58.6
Denmark	38	39.5	10.0	39.9	65.5
Estonia	2	9.3	0.0	13.1	14.7
Finland	78	87.4	81.3	74.3	106.7
France	489	40.2	19.6	38.9	60.5
Germany-CERTAIN*	266	23.9	7.9	25.4	39.1
Greece	45	29.0	2.1	29.4	52.5
Iceland	4	59.6	46.8	42.2	90.9
Ireland	80	79.3	30.6	64.0	145.6
Italy*	91	11.2	10.9	10.0	12.6
Latvia	6	19.7	9.3	9.9	41.5
Norway	49	52.2	29.8	40.2	86.1
Romania	52	17.0	5.1	14.7	30.4
Russia	430	20.0	10.4	20.8	30.7
Serbia	28	27.8	15.3	12.1	54.2
Slovakia	14	16.6	14.0	17.1	18.8
Slovenia	12	38.8	9.6	72.2	31.8
Spain	329	47.1	16.4	42.6	78.4
Turkey	346	18.5	10.5	14.5	30.1
Ukraine	105	16.1	6.2	10.1	33.1

* In 2017, 117 patients under the age of 21 years were transplanted in 18 transplantation centres in Germany. In Italy, deceased donor transplantation patients are not included; these numbers are an underestimation of true incidence.

Table 2: Prevalent Patients (continued)

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	26.3	32.2	23.3	1.9	3.9
Austria	56.9	22.8	3.2	4.7	32.4
Belarus	32.9	14.2	5.6	3.1	15.0
Bosnia and Herzegovina	25.1	11.3	11.0	0.0	7.4
Bulgaria	13.6	6.2	4.0	0.0	6.0
Cyprus	41.9	73.3	7.2	21.5	28.6
Czech Republic	32.9	19.8	3.0	3.0	20.5
Denmark	52.7	25.6	0.0	4.2	35.4
Estonia	9.1	9.6	0.0	0.0	9.3
Finland	105.3	68.8	3.4	3.4	80.7
France	47.2	32.9	7.2	4.0	29.0
Germany-CERTAIN*	29.1	18.5	-	-	23.7
Greece	33.9	23.9	10.3	11.0	7.7
Iceland	116.7	0.0	0.0	14.9	44.7
Ireland	87.3	71.0	9.9	12.9	56.5
Italy*	8.9	13.4	4.2	5.5	-
Latvia	25.5	13.6	0.0	6.6	13.1
Norway	62.3	41.6	0.0	2.1	50.1
Romania	15.5	18.5	10.1	4.9	2.0
Russia	24.7	15.0	2.5	7.3	10.2
Serbia	30.8	24.5	6.9	3.0	17.8
Slovakia	19.4	13.8	3.6	8.3	4.7
Slovenia	31.4	46.5	3.2	12.9	22.6
Spain	61.3	31.9	3.4	3.9	39.5
Turkey	18.9	17.5	3.1	9.3	5.7
Ukraine	17.5	14.5	4.6	3.1	8.4

* In 2017, 117 patients under the age of 21 years were transplanted in 18 transplantation centres in Germany. In Italy, deceased donor transplantation patients are not included; these numbers are an underestimation of true incidence.

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Publication list 2019

Boehm M, Bonthuis M, Noordzij M, Harambat J, Groothoff JW, Melgar AA, Buturovic J, Dusunsul R, Fila M, Jander A, Koster-Kamphuis L, Novljan G, Ortega PJ, Paglialonga F, Saravo MT, Stefanidis CJ, Aufricht C, Jager KJ, Schaefer F.
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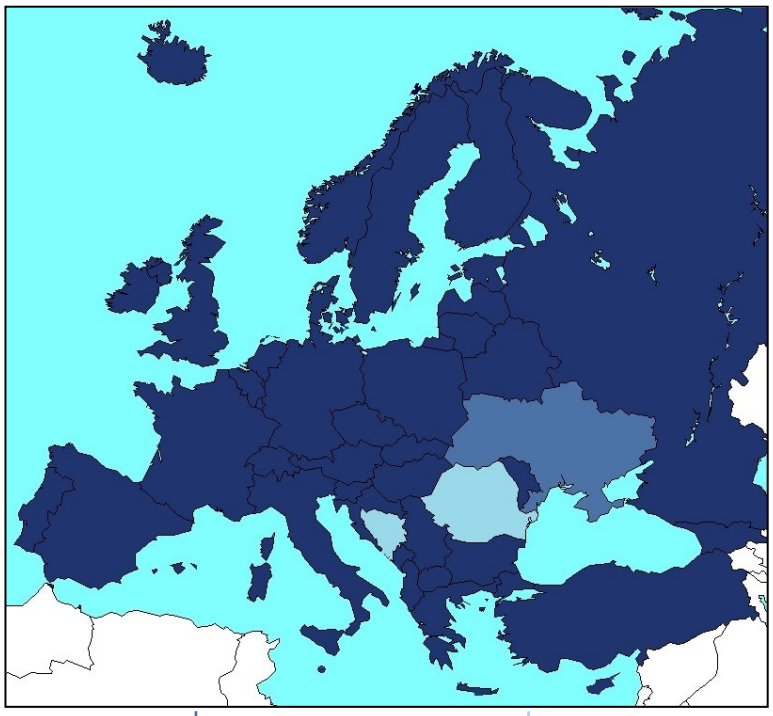

Provided extended data to the ESPN/ERA-EDTA Registry

Provided limited data to the ESPN/ERA-EDTA Registry

Provided data via the ERA-EDTA Registry

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