

An update on the Registry – January 2025



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Currently, 35 countries are participating in the ESPN/ERA Registry, providing information on more than 28,000 patients who started KRT before the age of 20 years.

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 sixteen subsequent years. This Annual Report shows epidemiological data on paediatric KRT in Europe for the year 2022.

In 2022, the incidence of KRT was 5.6 (range: 0.0 to 28.5) per million age-related population (pmarp) and the prevalence was 40.6 (range: 8.9 to 94.6) pmarp.

Five-year patient survival was 94.2% after the start of KRT and most patients for whom cause of death was reported, died of infections.

In 2024, two papers have been published and another one has been accepted for publication. The full publication list can be found below.

AJT published our paper on the clinical outcomes of paediatric KRT after childhood cancer. NDT published our paper on adult outcomes of childhood KRT in Europe from 2008 to 2019. Furthermore, our paper on access to kidney transplantation and re-transplantation in transplant candidates from childhood to adulthood has recently been accepted by NDT.

An important part of the Registry's research activities arise from the successful internship programme. In the past year, several fellows were hosted in the ESPN/ERA Registry:

- Henna Kajjansinkko, a paediatric nephrologist from Helsinki, Finland, worked on a project on KRT after cancer in children.
- Evgenia Preka from Paris, France, continued her part-time PhD trajectory at the Registry on re-transplantation in patients transplanted during childhood, from which one paper has recently been accepted for publication.
- Lucy Plumb, a paediatric nephrologist from Bristol, United Kingdom, started a project on sex differences in paediatric KRT patients.

If you are also interested in performing a research project at 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 are very proud of all the results, which would not have been possible without the great dedication and efforts of those who contribute to the ESPN/ERA Registry. We would like to thank all contributors for their fruitful collaboration and hope to keep working together in the future to improve paediatric nephrology care and research in Europe.

Table 1: Incident patients on KRT

Incident paediatric patients accepted for kidney replacement therapy in 2022 and general population characteristics in the same year.

| Country | Total | | General Population Characteristics | | |
|--|--------------|---------------------|------------------------------------|--------------------|-----------------------|
| | KRT patients | | Children | Total Population | Children |
| | N | 0-14 years pmarp | 0-14 years N | 0-99 years N | 0-14 years percent |
| Albania | 4 | 9.0 | 443.227 | 2.761.785 | 16.0 |
| Austria | 4 | 3.1 | 1.291.589 | 8.978.929 | 14.4 |
| Belarus | 6 | 3.9 | 1.534.402 | 9.255.524 | 16.6 |
| Bosnia and Herzegovina | 3 | 5.5 | 543.719 | 3.531.159 | 15.4 |
| Bulgaria | 3 | 3.1 | 953.243 | 6.643.323 | 14.3 |
| Croatia | 2 | 3.6 | 550.505 | 3.856.602 | 14.3 |
| Cyprus | 0 | 0.0 | 146.756 | 912.704 | 16.1 |
| Czech Republic | 6 | 3.5 | 1.722.109 | 10.672.120 | 16.1 |
| Denmark | 3 | 3.2 | 946.645 | 5.903.039 | 16.0 |
| Estonia | 2 | 9.1 | 220.859 | 1.348.840 | 16.4 |
| Finland ¹ | 7 | 8.3 | 846.061 | 5.556.104 | 15.2 |
| France | 76 | 6.4 | 11.827.399 | 68.022.451 | 17.4 |
| Germany-CERTAIN ² | 10 | 0.8 | 11.767.956 | 83.797.983 | 14.0 |
| Greece | 5 | 3.5 | 1.410.172 | 10.436.880 | 13.5 |
| Hungary | 2 | 1.4 | 1.401.612 | 9.644.377 | 14.5 |
| Iceland | 2 | 28.5 | 70.155 | 382.003 | 18.4 |
| Ireland | 0 | 0.0 | 1.007.979 | 5.165.700 | 19.5 |
| Italy ³ | 6 | 0.8 | 7.416.947 | 59.013.670 | 12.6 |
| Latvia | 0 | 0.0 | 300.234 | 1.879.383 | 16.0 |
| Lithuania | 0 | 0.0 | 422.256 | 2.831.639 | 14.9 |
| Malta | 0 | 0.0 | 69.483 | 531.508 | 13.1 |
| North Macedonia | 4 | 12.9 | 310.434 | 1.833.534 | 16.9 |
| Norway | 4 | 4.4 | 916.027 | 5.457.128 | 16.8 |
| Poland | 22 | 3.8 | 5.740.891 | 37.203.992 | 15.4 |
| Portugal | 4 | 3.0 | 1.337.947 | 10.409.706 | 12.9 |
| Republic of Serbia | 5 | 5.2 | 966.150 | 6.719.150 | 14.4 |
| Romania | 19 | 6.2 | 3.080.201 | 19.048.501 | 16.2 |
| Slovakia | 2 | 2.3 | 873.124 | 5.431.753 | 16.1 |
| Slovenia | 1 | 3.1 | 317.735 | 2.112.076 | 15.0 |
| Spain | 44 | 6.7 | 6.560.803 | 47.767.516 | 13.7 |
| Sweden | 17 | 9.3 | 1.834.097 | 10.486.944 | 17.5 |
| the Netherlands | 13 | 4.8 | 2.719.919 | 17.700.979 | 15.4 |
| Turkey ⁴ | 19 | 1.0 | 19.140.291 | 83.384.678 | 23.0 |
| Ukraine | 18 | 3.2 | 5.585.184 | 36.700.000 | 15.2 |
| UK (England, N. Ireland, Wales, Scotland) ⁵ | 98 | 8.4 | 11.615.595 | 67.596.281 | 17.2 |
| Total⁶ | 376 | 5.6 | 67.566.512 | 426.781.630 | 15.8 |

¹Data from Finland were provided on an aggregated level.

²Data from the German transplantation registry are based on 18 transplantation centres. In 2022, 130 patients under the age of 21 years were transplanted in Germany.

³The incidence in Italy is an underestimation of the true incidence, with coverage of 65% to 85% of all patients.

⁴The incidence in Turkey is an underestimation of the true incidence.

⁵In the UK the incidence is underestimated by approximately 7.5% due to one centre not providing data and patients opting out of data sharing for research purposes.

⁶Germany, Italy and Turkey were excluded from the overall incidence.

Table 2: Treatment modality at start of KRT in 2022

Treatment modality at day 1, among patients < 15 years of age starting KRT in 2022.
Patients from Germany, Italy, and Turkey are excluded.

| | N | Percent | Pmarp |
|-----------------------------|----------|----------------|--------------|
| HD at start | 168 | 44.7 | 2.5 |
| PD at start | 119 | 31.6 | 1.8 |
| Pre-emptive transplantation | 89 | 23.7 | 1.3 |
| Unknown | 0 | 0 | 0 |

Table 3: PRD distribution at start of KRT in 2022

Cause of kidney failure, among patients < 15 years of age, starting KRT in 2022.
According to new (2012/2018) and old (1995) ERA Registry PRD codes (Boerstra et al, Clin Kidney J 2023; 17(2): sfad281.)
Patients from Germany, Italy, and Turkey are excluded.

| | N | | Percent | | Pmarp | |
|--|------------|------------|----------------|------------|--------------|------------|
| | New | Old | New | Old | New | Old |
| CAKUT | 113 | 106 | 30.4 | 28.5 | 1.68 | 1.57 |
| Glomerulonephritis | 53 | 46 | 14.1 | 12.2 | 0.78 | 0.67 |
| Cystic kidney disease | 49 | 49 | 13.3 | 13.3 | 0.73 | 0.73 |
| Hereditary nephropathy | - | 24 | - | 5.4 | - | 0.30 |
| Metabolic and tubulointerstitial disorders | 19 | 15 | 5.1 | 4.1 | 0.28 | 0.22 |
| Toxic/ischemic renal failure | 9 | 5 | 2.4 | 1.4 | 0.13 | 0.07 |
| HUS | 20 | 20 | 5.4 | 5.4 | 0.30 | 0.30 |
| Vascular | 2 | 2 | 0.5 | 0.5 | 0.03 | 0.03 |
| Miscellaneous | 59 | 30 | 15.7 | 7.9 | 0.87 | 0.43 |
| Unknown | 52 | 79 | 13.0 | 21.4 | 0.72 | 1.18 |

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 KRT patients, aged < 15 years in 2022.
Patients from Germany, Italy, and Turkey are excluded.

| | N | Percent |
|--|----------|----------------|
| eGFR<8 ml min ⁻¹ per 1.73 m ² | 63 | 46.7 |
| eGFR 8 - 15 ml min ⁻¹ per 1.73 m ² | 57 | 42.2 |
| eGFR>15 ml min ⁻¹ per 1.73 m ² | 15 | 11.1 |

Table 5: Prevalent Patients on KRT

Prevalent paediatric patients on kidney replacement therapy on the 31st of December 2022.
Prevalent counts and prevalence per million age-related population, by age groups.

| Country | Total KRT | | Age Groups | | |
|--|-------------|---------------------|--------------------|--------------------|----------------------|
| | N | 0-14 years pmarp | Infants | Children | Adolescents |
| | | | 0-4 years pmarp | 5-9 years pmarp | 10-14 years pmarp |
| Albania | 13 | 29.3 | 22.7 | 45.6 | 19.0 |
| Austria | 46 | 35.6 | 20.8 | 39.1 | 47.1 |
| Belarus | 43 | 28.0 | 21.6 | 15.6 | 46.1 |
| Bosnia and Herzegovina | 5 | 9.2 | 5.7 | 0.0 | 20.8 |
| Bulgaria | 14 | 14.7 | 6.7 | 15.6 | 20.8 |
| Croatia | 29 | 52.7 | 5.7 | 50.2 | 97.1 |
| Cyprus | 7 | 47.7 | 0.0 | 41.0 | 101.7 |
| Czech Republic | 36 | 20.9 | 12.5 | 14.1 | 35.4 |
| Denmark | 33 | 34.9 | 16.1 | 29.6 | 57.3 |
| Estonia | 6 | 27.2 | 0.0 | 41.1 | 38.3 |
| Finland ¹ | 80 | 94.6 | 83.1 | 96.6 | 101.5 |
| France | 497 | 42.0 | 14.6 | 41.5 | 65.2 |
| Germany-CERTAIN ² | 300 | 25.5 | 5.8 | 29.9 | 41.5 |
| Greece | 30 | 21.3 | 7.2 | 13.0 | 39.3 |
| Hungary | 48 | 34.2 | 21.5 | 27.9 | 53.3 |
| Iceland | 6 | 85.5 | 131.4 | 89.0 | 40.2 |
| Ireland | 9 | 8.9 | 3.3 | 17.8 | 5.4 |
| Italy ³ | 195 | 26.3 | 8.5 | 23.7 | 42.0 |
| Latvia | 6 | 20.0 | 10.9 | 18.5 | 29.9 |
| Lithuania | 11 | 26.1 | 15.7 | 20.4 | 40.7 |
| Malta | 1 | 14.4 | 0.0 | 42.2 | 0.0 |
| North Macedonia | 12 | 38.7 | 31.5 | 27.6 | 56.4 |
| Norway | 46 | 50.2 | 21.5 | 58.6 | 66.7 |
| Poland | 229 | 39.9 | 14.5 | 35.5 | 66.5 |
| Portugal | 56 | 41.9 | 9.6 | 53.2 | 59.2 |
| Republic of Serbia | 29 | 30.0 | 3.2 | 30.8 | 54.9 |
| Romania | 60 | 19.5 | 5.2 | 15.6 | 35.8 |
| Slovakia | 18 | 20.6 | 10.3 | 20.4 | 31.3 |
| Slovenia | 13 | 40.9 | 10.3 | 65.3 | 44.0 |
| Spain | 331 | 50.5 | 21.6 | 39.0 | 81.2 |
| Sweden | 92 | 50.2 | 22.3 | 49.8 | 76.3 |
| the Netherlands | 118 | 43.4 | 12.7 | 31.2 | 82.6 |
| Turkey ⁴ | 361 | 18.9 | 5.3 | 21.4 | 29.5 |
| Ukraine | 117 | 20.9 | 7.0 | 23.2 | 28.2 |
| UK (England, N. Ireland, Wales, Scotland) ⁵ | 704 | 60.6 | 21.8 | 53.3 | 101.3 |
| Total⁶ | 2745 | 40.6 | 16.1 | 37.1 | 64.5 |

¹Data for Finland were provided on an aggregated level.

²Data from the German transplantation registry are based on 18 transplantation centres. In 2022, 130 patients under the age of 21 years were transplanted in Germany.

³The prevalence in Italy is an underestimation of the true prevalence, with coverage of 65% to 85% of all patients.

⁴The prevalence in Turkey is an underestimation of the true prevalence.

⁵In the UK the prevalence is underestimated by approximately 8.4% due to one centre not providing data and patients opting out of data sharing for research purposes.

Table 5: Prevalent Patients on KRT (continued)

Prevalent paediatric patients on kidney replacement therapy on the 31st of December 2022.
Prevalent counts and prevalence per million age-related population, by sex 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 | 31.1 | 27.5 | 22.6 | 2.3 | 4.5 |
| Austria | 46.7 | 23.9 | 0.8 | 2.3 | 32.5 |
| Belarus | 41.0 | 13.1 | 1.3 | 5.9 | 20.9 |
| Bosnia and Herzegovina | 10.8 | 7.6 | 7.4 | 0.0 | 1.8 |
| Bulgaria | 16.3 | 12.9 | 2.1 | 1.0 | 11.5 |
| Croatia | 56.6 | 48.5 | 1.8 | 32.7 | 18.2 |
| Cyprus | 52.9 | 42.2 | 6.8 | 20.4 | 20.4 |
| Czech Republic | 23.8 | 17.8 | 2.3 | 7.0 | 11.6 |
| Denmark | 53.5 | 15.2 | 1.1 | 3.2 | 30.6 |
| Estonia | 17.7 | 37.2 | 0.0 | 0.0 | 27.2 |
| Finland ¹ | 111.0 | 77.4 | 1.2 | 1.2 | 92.2 |
| France | 49.7 | 33.9 | 6.8 | 3.0 | 32.0 |
| Germany-CERTAIN ² | 32.6 | 18.0 | - | - | 25.0 |
| Greece | 30.3 | 11.7 | 7.8 | 4.3 | 9.2 |
| Hungary | 41.7 | 26.4 | 2.9 | 5.7 | 25.0 |
| Iceland | 110.6 | 58.8 | 14.3 | 14.3 | 57.0 |
| Ireland | 11.6 | 6.1 | 0.0 | 2.0 | 6.9 |
| Italy ³ | 33.8 | 18.3 | 2.3 | 5.7 | 18.3 |
| Latvia | 19.4 | 20.6 | 0.0 | 6.7 | 13.3 |
| Lithuania | 36.9 | 14.6 | 2.4 | 11.8 | 11.8 |
| Malta | 27.8 | 0.0 | 0.0 | 0.0 | 14.4 |
| North Macedonia | 49.9 | 26.6 | 3.2 | 9.7 | 25.8 |
| Norway | 61.6 | 38.2 | 1.1 | 1.1 | 46.9 |
| Poland | 49.5 | 29.7 | 4.7 | 7.3 | 27.7 |
| Portugal | 52.5 | 30.7 | 3.0 | 9.0 | 29.9 |
| Republic of Serbia | 40.2 | 19.2 | 4.1 | 15.5 | 9.3 |
| Romania | 21.5 | 17.4 | 12.3 | 2.9 | 4.2 |
| Slovakia | 20.1 | 21.1 | 3.4 | 13.7 | 3.4 |
| Slovenia | 48.9 | 32.4 | 9.4 | 12.6 | 18.9 |
| Spain | 63.4 | 36.8 | 4.6 | 2.9 | 42.8 |
| Sweden | 53.0 | 47.2 | 1.1 | 5.5 | 43.6 |
| the Netherlands | 48.1 | 38.5 | 1.8 | 2.6 | 39.0 |
| Turkey ⁴ | 20.0 | 17.7 | 2.2 | 7.6 | 9.0 |
| Ukraine | 23.6 | 18.3 | 3.8 | 3.9 | 13.2 |
| UK (England, N. Ireland, Wales, Scotland) ⁵ | 75.0 | 45.5 | 7.1 | 7.0 | 46.6 |
| Total⁶ | 49.3 | 31.5 | 5.1 | 5.2 | 30.3 |

¹Data from Finland were provided on an aggregated level.

²Data from the German transplantation registry are based on 18 transplantation centres. In 2022, 130 patients under the age of 21 years were transplanted in Germany.

³The prevalence in Italy is an underestimation of the true prevalence, with coverage of 65% to 85% of all patients.

⁴The prevalence in Turkey is an underestimation of the true prevalence.

⁵In the UK the prevalence is underestimated by approximately 8.4% due to one centre not providing data and patients opting out of data sharing for research purposes.

⁶Germany, 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 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 | 46.3 (44.7-47.9) | 27.6 (26.6-28.6) |
| Mean z-score systolic blood pressure | 1.32 (1.27-1.36) | 0.81 (0.78-0.83) |
| Mean z-score diastolic blood pressure | 1.18 (1.14-1.22) | 0.72 (0.69-0.74) |
| Height | | |
| % of patients with height z-score < -2 | 46.5 (45.3-47.8) | 37.6 (36.5-38.8) |
| Mean height z-score | -1.88 (-1.93;-1.82) | -1.70 (-1.74;-1.66) |

Figure 1: Five-year patient survival

Incident KRT patients under the age of 15 years starting KRT from 2007 onwards. Follow-up until 31st of December 2022.

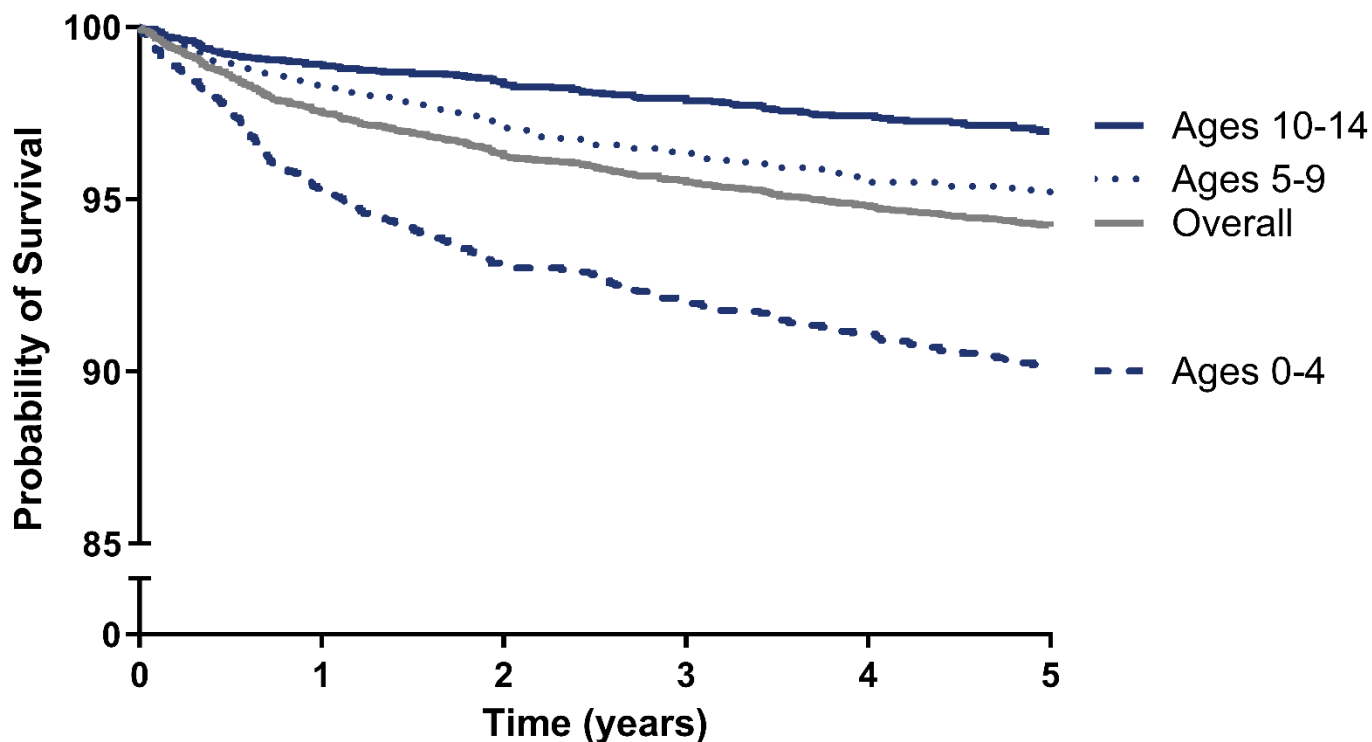


Table 7: Causes of Death

Causes of death according to the ERA Registry coding list.

Incident KRT patients < 15 years starting KRT from 2007 onwards are included. Follow-up until 31st of December 2022.

| Cause of death | Number of deaths | Percent |
|---|------------------|---------|
| Myocardial ischemia and infarction | 5 | 0.8 |
| Cardiac failure | 51 | 7.8 |
| Cardiac arrest/sudden death other cause | 60 | 9.2 |
| Cerebro-vascular accident | 23 | 3.5 |
| Infection | 141 | 21.6 |
| Suicide/refusal or cessation of treatment | 3 | 0.5 |
| Treatment withdrawn | 18 | 2.8 |
| Cachexia | 1 | 0.2 |
| Malignant disease | 32 | 4.9 |
| Other identified cause of death | 109 | 16.7 |
| Cause of death uncertain/not determined | 209 | 32.1 |

ESPN/ERA Registry Scientific Committee

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ESPN/ERA Registry

Department of Medical Informatics

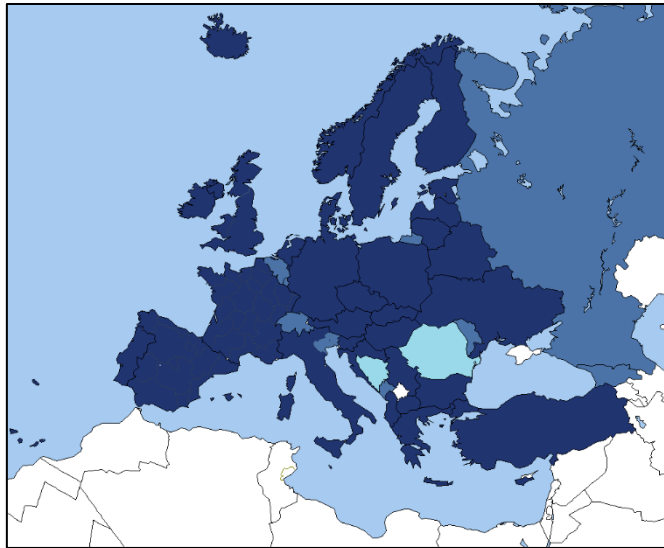
Amsterdam University Medical Centers, location AMC

Publication list 2024

1. Adult outcomes of childhood kidney replacement therapy in Europe from 2008 to 2019: an ERA Registry study. Montez de Sousa IR, Bonthuis M, Kramer A, Ordoñez FA, de la Cerda Ojeda F, Rydell H, Helve J, Groothoff JW, Hommel K, Buchwinkler L, Segelmark M, Arici M, Palsson R, Bell S, Trujillo-Alemán S, Bakkaloglu SA, Sørensen SS, Vila A, Ortiz A, Stel VS, Jager KJ. *Nephrol Dial Transplant.* 2024 (Online ahead of print).

2. Clinical outcomes of pediatric kidney replacement therapy after childhood cancer – An ESPN/ERA Registry study. Kaijansinkko H, Bonthuis M, Jahnukainen K, Harambat J, Vidal E, Bakkaloglu SA, Inward C, Sinha MD, Roperto RM, Kuehni CE, Biró E, Kwon T, Mota C, Adams B, Szczepańska M, Bieniasz B, Höcker B, Fomina S, Gjerstad AC, Vondrak K, Alpay H, Plumb LA, Hommel K, Molchanova MS, Hubmann H, Alonso-Melgar A, Jager KJ, Jahnukainen T. *Am J Transplant.* 2024 (Online ahead of print).

3. Access to transplantation and re-transplantation in European kidney transplant candidates from childhood to adulthood: Long-term data from the ERA Registry. Preka E, Bonthuis M, Marks SD, Kramer A, de Vries APJ, Sørensen SS, Bakkaloglu SA, Bistrup C, Jahnukainen T, Rodriguez Arévalo OL, Buchwinkler L, Segelmark M, Sanchez JE, Arnol M, Ordóñez-Álvarez FA, de la Cerda-Ojeda F, Plumb LA, Methven S, Palsson R, Lundgren T, Ríos H, Ortiz A, Stel VS, Harambat J, Jager KJ. *Nephrol Dial Transplant* (Accepted for publication).



Provided extended data to the ESPN/ERA Registry in 2024

Provided data to the ESPN/ERA Registry before 2024

Provided data via the ERA Registry

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

| | | | |
|---------------------------|---|--|---|
| Albania | D Shtiza | Latvia | A Popova, S Derkevica, V Kuzema |
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| Croatia | I Kos, I Jakopcic, J Ivancic, M Ban, H Matkovic, M Davidovic, L Lamot, K Vrljičak A Elia | Poland | A Zurowska, I Zagozdzon |
| Cyprus | K Vondrak | Portugal | C Mota, JE Esteves, M Abranches, C Gomes |
| Czech Republic | K Hommel | Romania | G Mircescu, L Garneata, and E Podgoreanu |
| Denmark | Ü Toots | Russia | EA Molchanova, EV Zakharova, AM Andrusev |
| Estonia | J Helve, P Finne | Scotland | Scottish Renal Registry team |
| Finland | C Couchoud, M Lassalle, J Hogan | Serbia | M Kostić, B Spasojević, M Cvetković, I Gojković, D Paripović, G Miloševski-Lomić |
| France | T Davitaia | Slovakia | L Podracka, G Kolvek |
| Georgia | K Krupka, B Höcker, L Pape, B Tönshoff | Slovenia | N Battelino, G Novljan, J Buturovic-Ponikvar |
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| Greece | G Reusz, O Horváth, Cs Berecki, A Szabó, T Szabó, O Lakatos | Sweden | KG Prütz, M Stendahl, M Evans, T Lundgren, H Rydell, and M Segelmark |
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| Ireland | B Gianoglio, I Guzzo, E la Porta, F Paglialonga, C Corrado, E Vidal, E Verrina | Turkey | S Bakkaloglu |
| Italy | | Ukraine | SP Fomina |
| | | United Kingdom, England/Wales/ Northern Ireland | All the staff of the UK Renal Registry and of the renal units submitting data |
| | | United Kingdom, Scotland | All of the Scottish Renal Registry team |