

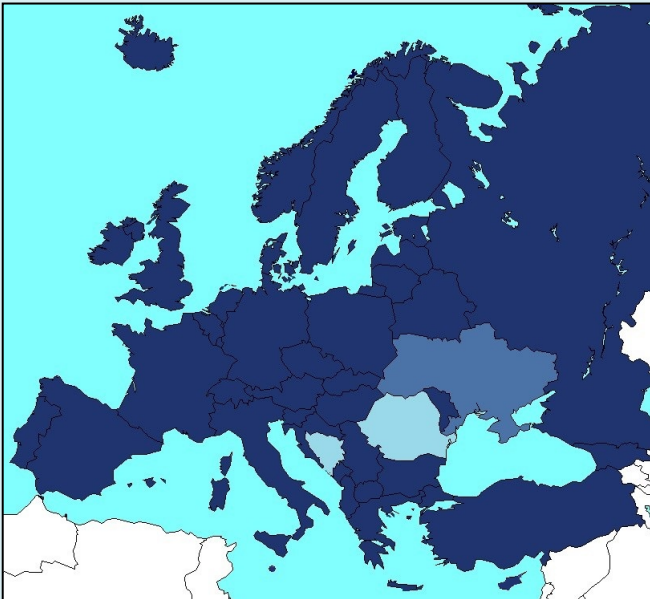
ESPN <https://espn-online.org>




ESPN/ERA Registry <https://www.espn-reg.org>

ESPN/ERA Registry Scientific Committee

Enrico Vidal, Italy, chair*
Sevcan Bakkaloglu, Turkey, vice-chair*
Dieter Haffner, Germany
Jun Oh, Germany
Kitty Jager, the Netherlands
Manish Sinha, United Kingdom
Timo Jahnukainen, Finland
Alberto Ortiz, Spain

*ESPN representatives on the ERA
Registry Committee



-  Provided extended data to the ESPN/ERA Registry
-  Provided limited data to the ESPN/ERA Registry
-  Provided data via the ERA Registry

Highlights of 2023

We are happy to update you on the latest news and activities of the ESPN/ERA Registry.

With the help of all data contributors we were able to publish 3 papers in 2023 (please see below for further details). Furthermore, several others are in preparation.

We can look back at a successful ESPN Congress in Vilnius. There were three presentations based on Registry data and we have been involved in many interesting discussions leading to new and exciting research ideas. The Registry Symposium was well-attended, underscoring the importance of paediatric kidney registries.

But there is more!

A comprehensive Annual Report for the years 2020 and 2021 is in preparation and close to be finalized. The Annual Report will show data from paediatric KRT patients in 34 European countries. Furthermore, we are working on a manuscript describing demographics of paediatric KRT patients in Europe based on 15-years of data collection within the ESPN/ERA Registry. We would like to thank everyone who is actively involved in the data collection and collaborating with the ESPN/ERA Registry, without your huge efforts the Registry would not have been this successful.

We are very grateful with the great commitment and enthusiasm within the European paediatric nephrology community, which enabled us to host two fellows this year, and many more are scheduled for next year. **If you are also interested in performing a research project on the Registry, or when you would like to know more about participating in the ESPN/ERA Registry, please let us know.**

Elections ESPN/ERA Registry Committee

In 2024, the terms of several ESPN/ERA Registry Committee members will end, and there will be two vacant positions for national representatives, and a vice-chair position.

The Registry Committee supervises the work of the Registry on behalf of the ESPN Council, the ERA Council and the national registries providing data to the ESPN/ERA Registry. The Registry Committee members are elected for a 3-year term with the possibility to be re-elected for one additional term. The Committee has regular meetings (both online and face-to-face during the ESPN Congress). During the meetings, the progress of the Registry is discussed and future plans are made. You will also be actively involved in the scientific work of the Registry.

Please let us know if you are interested in one of these positions. We very much look forward to collaborating with you.

Publications 2023

Schild R, Dupont S, Harambat J, Vidal E, Balat A, Berezki C, Bieniasz 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.

Disparities in treatment and outcome of kidney replacement therapy in children with comorbidities: an ESPN/ERA Registry study.

Clin Kidney J. 2023;16(4):745-755.

Bakkaloglu SA, Vidal E, Bonthuis M, Neto G, Paripović D, Åsberg A, Hijosa MM, Vondrak K, Jankauskiene A, Roussinov D, Awan A, Jager KJ.

European chronic kidney disease registries for children not on kidney replacement therapy: tools for improving health systems and patient-centred outcomes.

Clin Kidney J. 2023;16(11):1980-1985.

Bonthuis M, Bakkaloglu SA, Vidal E, Baiko S, Braddon F, Errichiello C, Francisco T, Haffner D, Lahoche A, Leszyńska B, Masalkiene J, Stojanovic J, Molchanova MS, Reusz G, Barba AR, Rosales A, Tegeltija S, Ylinen E, Zlatanova G, Harambat J, Jager KJ.

Associations of longitudinal height and weight with clinical outcomes in pediatric kidney replacement therapy: results from the ESPN/ERA Registry.

Pediatr Nephrol. 2023;38(10):3435-3443.

ESPN/ERA Registry

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European paediatric CKD registries

By Sevcan Bakkaloglu

Chronic kidney disease (CKD) in children, from birth to late adolescence, is a unique and highly challenging condition that requires epidemiological research and large-scale prospective cohort studies to develop evidence-based strategies to slow down the progression of CKD. The ESPN/ERA Registry has collected data on patients on kidney replacement therapy (KRT) for a total of 15 years, still a Europe-wide paediatric CKD registry has yet to exist.

A survey was sent to national representatives collaborating within the ESPN/ERA Registry framework to collect information on whether they are running CKD registries in children. Questions on the general characteristics of the national registry and detailed data on anthropometry, laboratory tests, and given medications at baseline and follow-up were included. Among 38 European countries, eight existing CKD registries have been identified. This initiative has raised awareness that eight European countries are collecting routine paediatric CKD data on a national or regional basis.

In adults, only six European countries are engaged in routine data collection of patients with CKD stages 4–5, and one is preparing to do so. These attempts are promising for establishing a collective European paediatric CKD registry. Furthermore, establishing a CKD registry linked to the ESPN/ERA Registry and subsequently linking it to the adult KRT data from the ERA Registry would bring numerous advantages. We would be able to monitor disease progression and develop early and effective measures for the management of modifiable risk factors for preventing disease progression in childhood and beyond as a continuum. Through such linkages, gaps in patient follow-up would be eliminated, and patient-centered outcomes may be improved. As we would have data from a high number of patients, another future prospect would be the development of artificial intelligence based prediction models for disease progression or for reaching end-stage kidney disease (ESKD).

The results of the survey have been recently published in *Clin Kidney J.* For more details please see the Publication list.

Key figures of 15 years of ESPN/ERA Registry



Data from **28,663** individual patients on **102** variables for **15** consecutive years



51 papers published in 12 medical journals resulting in **461** authorships from **259** unique authors



22 research fellows from **10** countries