

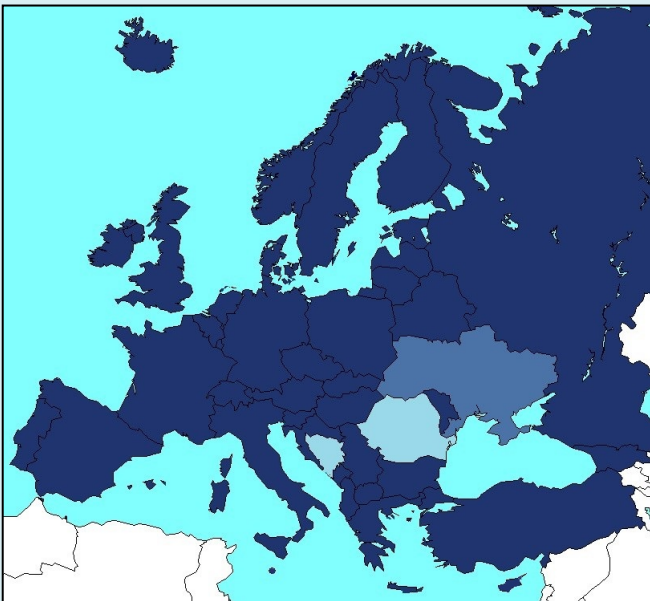
ESPN <https://espn-online.org>




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 2022

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 1 paper in 2022 (please see below for further details). Furthermore, two more papers are submitted (one on comorbidities and one on anthropometry and clinical outcomes), and several others are in preparation. A recent inventory about existing national paediatric registries collecting data on children with CKD not on dialysis has been performed and a paper on this topic is going to be submitted soon.

With three (hybrid) presentations based on Registry data, we look back at a successful ESPN congress in Ljubljana.

Due to maternity leave of the ESPN/ERA Registry Coordinator no Annual Report has been published this year, but you may expect a comprehensive Annual Report next year, including patient data for the years 2020 and 2021.

But there is more!

After obtaining the ISO 27001 certification on Information Security last year, last May the Registry also obtained the ISO 9001 certification. This is the international standard specifying criteria and requirements for a quality management system. In order to meet these ISO standards we are constantly reflecting and improving our information systems and working methods. An important step in this, would be to introduce two factor authentication for the online data collection tool. This would require both a password and a security code (sent by text message) to log in and enter patient data. We plan to have this system fully operational in the beginning of 2023.

We also would like to share some changes in the Registry office staff. Marjolein Bonthuis will start working at the (adult) ERA Registry, but will still be involved in the ESPN/ERA Registry for one day per week. At the same time, Iris Montez de Sousa, a PhD student, will gradually take over her tasks. She will introduce herself below. All the ESPN/ERA Registry Scientific Committee's members would like to take this opportunity to express their gratitude for the great contribution of Marjolein to the ESPN Registry growth in these years, but we are still looking forward to a new type of collaboration in the coming months!

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.**

Publications 2022

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.

Kidney transplantation in small children: Association between body weight and outcome- A report from the ESPN/ERA-EDTA Registry.

Transplantation 2022;106(3):607-614.

ESPN/ERA Registry

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Partial Goodbye

By Marjolein Bonthuis

After working with great pleasure for the ESPN/ERA Registry for over 12 years, it is now time for a new challenge. But don't worry, I will still be involved in the Registry. From January 2023, I will be working for both the ESPN/ERA (1 day/week) and the ERA Registry (3 days/week). Iris Montez de Sousa, a PhD student will succeed me at the ESPN/ERA Registry and I will train and supervise her. My new position will provide the unique opportunity to extend our work on the strategic topic of the transition period from paediatric to adult kidney replacement therapy (KRT).

So, this is not a complete goodbye, as we will still collaborate in research projects. I would like to thank all of you for your great dedication to the paediatric nephrology field and keeping up the ESPN/ERA Registry.

I will keep enjoying being part of this warm and close community, thank you!

Introducing Iris Montez de Sousa



From December 2022 I have been working on the Registry as a PhD student. I did my Master in Nutrition and Health with specialization in Epidemiology and Public Health at Wageningen University, the Netherlands.

The main focus of my PhD project will be on the epidemiology of kidney replacement therapy in young adults transferring from paediatric to adult nephrology care. The period of adolescence and early adulthood is challenging, because of high graft failure rate, due to low medication adherence, and it might be exacerbated by the transition from paediatric to adult nephrology care. However, young adults that started kidney replacement therapy during childhood are still an under-researched group. Registry studies can provide a valuable source of information on this challenging population. I will be working with both the paediatric and adult datasets to obtain further epidemiological insights in this group.

In Europe, following patients from childhood into adulthood is complicated by the fact that data on paediatric and adult KRT patients is collected by two separate registries. However, as both registries are hosted by the Amsterdam University Medical Centre, location AMC, this provides us the opportunity to investigate possibilities of linking data from childhood to adulthood. We plan to publish a brief report on this important topic soon.

I am very happy to join the Registry team and look forward to collaborating with you all!

