

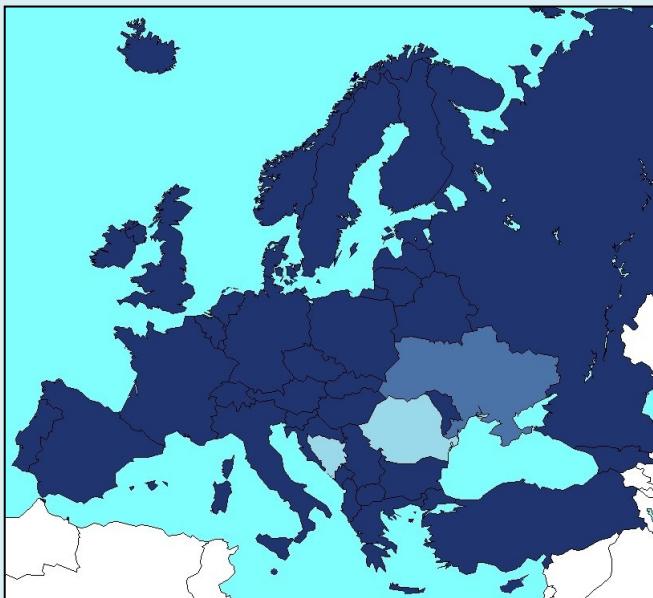
ESPN <https://espn-online.org>ESPN/ERA-EDTA Registry <https://www.espn-reg.org>

ESPN/ERA-EDTA Registry

Scientific Committee

Jérôme Harambat, France, chairman*
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*ESPN representatives on the ERA-EDTA Registry Committee



 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

ESPN/ERA-EDTA Registry

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Highlights of 2019

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

In order to harmonize data privacy across Europe and to protect and empower all EU citizens data privacy the European General Data Protection Regulation was enforced in May 2018. To comply with this regulation the ESPN/ERA-EDTA Registry sent Data Transfer Agreements (DTAs) to all national registries contributing with data. As of December 2019, DTAs are concluded with 28 out of 40 contributing countries. For the remainder of countries the DTAs are still pending.

With the help of all those who contributed with data we were able to publish 4 papers and a Letter to the Editor in 2019 (see list of publications for further details). Several other papers have been submitted or are in preparation.

In 2019, Evgenia Preka, a paediatric nephrologist from the United Kingdom, started her (part-time) PhD project at the ESPN/ERA-EDTA Registry. She will perform the PhD project besides her clinical work in the UK. As part of her thesis she wrote a Letter to the Editor on starting dialysis in children, which was recently published in JASN. Please find more information below.

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-EDTA Registry, please let us know.

We would also like to thank all the contributors of the Registry and look forward to collaborating with you in 2020!



IPNA congress Venice

During the 18th IPNA congress in Venice there were two oral presentations based on Registry data: Jaap Grootenhoff presented on clinical aspects of children on dialysis and Enrico Vidal presented data on longitudinal changes of blood pressure in children on RRT.

Additionally, five posters were presented, one on comorbidities, one on prevalence and predictors of hypertension, one on anthropometry and clinical outcomes, one on the minimal weight at transplantation in small children, and one on ten year trends in paediatric RRT in Europe.

Publications 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 F, Ortega PJ, Paglialonga F, Saravo MT, Stefanidis CJ, Aufrecht C, Jager KJ, Schaefer F.

Hemodialysis vascular access and subsequent transplantation: a report from the ESPN/ERA-EDTA Registry.

Pediatr Nephrol. 2019 Apr;34(4):713-721.

Bonthuis M, Groothoff JW, Ariceta G, Baiko S, Battelino N, Bjerre A, Cransberg K, Kolvek G, Maxwell H, Miteva P, Molchanova MS, Neuhaus TJ, Pape L, Reusz R, Rousset-Rouviere C, Sandes AR, Topaloglu R, van Dyck M, Ylinen E, Zagazdzon I, Jager KJ, Harambat J.

Growth patterns after kidney transplantation in European children over the past 25 years: an ESPN/ERA-EDTA Registry Study.

Transplantation. 2019 Apr [Epub ahead of print].

Preka E, Bonthuis M, Harambat J, Jager KJ, Groothoff JW, Baiko S, Bayazit AK, Boehm M, Cvetkovic M, Edvardsson VO, Fomina S, Heaf JG, Holtta T, Kis E, Kolvek G, Koster-Kamphuis L, Molchanova EA, Muñoz M, Neto G, Novljan G, Printza N, Sahapazova E, Sartz L, Sinha MD, Vidal E, Vondrak K, Vrillon I, Weber LT, Weitz M, Zagazdzon I, Stefanidis CJ, Bakkaloglu SA.

Association between timing of dialysis initiation and clinical outcomes in the paediatric population: an ESPN/ERA-EDTA Registry study.

Nephrol Dial Transplant. 2019 Nov 1;34(11):1932-1940.

Drube J, Wan M, Bonthuis M, Wühl E, Bacchetta J, Santos F, Grenda R, Edefonti A, Harambat J, Shroff R, Tönshoff B, Haffner D; ESPN CKD-MBD, Dialysis, and Transplantation WG.

Clinical practice recommendations for growth hormone treatment in children with chronic kidney disease.

Nat Rev Nephrol. 2019 Sep;15(9):577-589;

Preka E, Bonthuis M, Harambat J, Jager KJ.

Think twice before postponing chronic dialysis in children.

J Am Soc Nephrol. 2019 Dec;30(12):2473-2474.

Fellowships at the Registry

We very much welcome (paediatric) nephrologists and researchers to perform scientific projects on Registry data. This way, we hope to increase cross-border medical knowledge and promote evidence-based practices in paediatric nephrology. Our internship programme has been very successful in the past and 19 internships have been performed so far. A brief overview of the performed internships can be found on our website (<https://www.espn-reg.org/index.jsp?p=int>).

Funding possibilities are available from the ESPN or the ERA-EDTA. For more information please contact the Registry coordinator.

Think twice before postponing chronic dialysis in children

By Evgenia Preka

Paediatric Nephrologist, Southampton (UK)

As demonstrated by various papers studying the effect of starting dialysis early or late in children with end-stage kidney disease, there is no clear guidance for the optimal time to initiate chronic dialysis in children purely based on eGFR. All these studies in the paediatric population were observational studies with data from European, NAPRCTS and International Registry databases and their outcomes might have shown an over- or under-estimation of the effects measured (survival, access to transplantation, cardiovascular mortality/morbidity and growth), as those studies include statistical inborn errors (lead time, indication and immortal time biases).

The only RCT conducted in adults (the IDEAL study) revealed no differences in all-cause mortality, economics or quality of life and taken under consideration all the above, this should guide current practice until further RCTs are conducted in children. We hope that our recent letter in JASN created awareness regarding this issue for all clinicians before generalizing results purely based on observational data.

Obviously, interpretation of bias cannot be limited to a simple inquisition: is bias present or not? Researchers/clinicians should each time evaluate the validity of the study design and identify the study biases. We hope, by the example in this letter, to empower a mindset of scientific quality and interpretation besides enhancing patient safety and outcomes.

