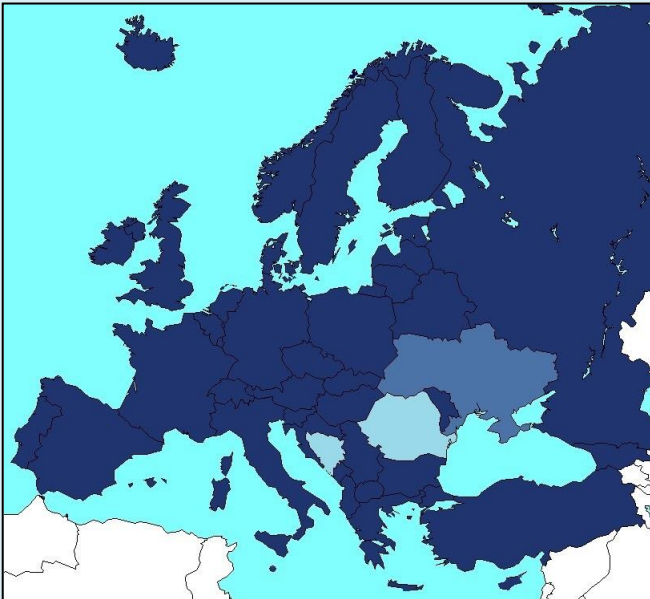





ESPN/ERA Registry Scientific Committee

Enrico Vidal, Italy, chair*
 Sevcan Bakkaloglu, Turkey, vice-chair*
 Rezan Topaloglu, Turkey
 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 2021

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 2021 (please see list of publications for further details), and several other papers have been submitted or are in preparation.

Since September we have a new chair of the Registry, Enrico Vidal succeeded Jérôme Harambat. Please find a piece from both of their hands below. Sevcan Bakkaloglu from Turkey has been elected as the vice chair on the Registry.

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.

Time for reflection

By Jérôme Harambat



Kidney failure in children is a rare, but life-long and devastating condition. Its prevalence continues to increase in Europe highlighting the importance of collaborative CKD research.

I have had the honour and the great opportunity to collaborate with the ESPN/ERA-EDTA (now named ESPN/ERA) Registry for the past 10 years, initially as young research fellow eager to learn epidemiology at the Amsterdam office of the Registry and more recently as vice-chair and then chair of the scientific committee until the end of my term in 2021. Since it was launched in 2007, the ESPN/ERA Registry has been a unique epidemiological tool devoted to the European Society for Pediatric Nephrology (ESPN) and contributed significantly to advancing knowledge in the field of pediatric kidney replacement therapy (KRT).

Over the last 12 years, the Registry collected data on 24,000 patients from 40 European countries using about 100 variables. It hosted 22 research fellows from 11 countries, published almost 50 papers, and provided more than 400 authorships to the ESPN community.

What has been achieved so far by this successful collaborative ESPN/ERA Registry study?

Publications 2021

Bonthuis M, Vidal E, Bjerre A, Aydoğ Ö, Baiko S, Garneata L, Guzzo I, Heaf JG, Jahnukainen T, Lilien M, Mallett T, Mirescu G, Molchanova EA, Nüsken E, Rascher K, Roussinov D, Szczepanska M, Tsimaratos M, Varvara A, Verrina E, Veselinović B, Jager KJ, Harambat J.

Ten-year trends in epidemiology and outcomes of pediatric kidney replacement therapy in Europe: data from the ESPN/ERA-EDTA Registry.
Pediatr Nephrol. 2021; 36(8):2337-2348..

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

Growth in children on kidney replacement therapy: a review of data from patient registries.
Pediatr Nephrol. 2021(8); 36: 2563-2574.

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 2021(Online ahead of print).

Time for reflection – continued

By Jérôme Harambat

I would like to highlight some of the major findings of the Registry in the area of KRT in children and to outline ongoing opportunities to tackle inequalities between regions in CKD care of European children. Indeed, kidney health disparities across Europe have been a major focus of investigation for the Registry. Specifically, we have shown that the burden of kidney failure falls disproportionately upon children from lower income European regions who have reduced access to KRT, lower access to transplantation when dialysis is initiated, and higher mortality, but similar kidney graft survival for those who got a transplant (Chesnaye et al. *Nephrol Dial Transplant* 2015; Chesnaye et al. *Lancet* 2017; Bonthuis et al. *Kidney Int* 2020).

Landmark publications of the Registry have better defined the outcomes of neonates and infants receiving KRT (van Stralen et al. *Kidney Int* 2014; Vidal et al. *Am J Kidney Dis* 2017) providing valuable data that help pediatric nephrology teams to counsel families. Other Registry results identified areas of improvement for clinical care with current suboptimal treatment of cardiovascular risk factors (Kramer et al. *Kidney Int* 2011; Bonthuis et al. *Nephrol Dial Transplant* 2014) and growth failure (Harambat et al. *Clin J Am Soc Nephrol* 2014; Bonthuis et al. *Transplantation* 2020), and strengthened the evidence that management of rare kidney diseases has improved substantially over time (van Stralen et al. *Clin J Am Soc Nephrol* 2011; Harambat et al. *Clin J Am Soc Nephrol* 2012; Mekhali et al. *Am J Kidney Dis* 2016).

The Registry's contribution to the clinical care of children on KRT also includes population-based epidemiological data useful for healthcare planning such as updated incidence/prevalence (Bonthuis et al. *Pediatr Nephrol* 2021) and mortality (Chesnaye et al. *Kidney Int* 2016), kidney failure recovery rate (Bonthuis et al. *Clin J Am Soc Nephrol* 2018), and optimal timing of KRT initiation (Preka et al. *Nephrol Dial Transplant* 2019).

Personally, it has been a very enriching period for me in my different roles for the Registry, both from a scientific and a human point of view. I wish a bright future to the Registry, which has all my support, and I strongly encourage young clinicians, research fellows, and all ESPN members to get involved in this important endeavor for our pediatric nephrology community.

ESPN/ERA Registry

Marjolein Bonthuis (Registry coordinator)
Department of Medical Informatics
Academic Medical Center
Room J1B-125
1105 AZ Amsterdam
The Netherlands

Email: m.bonthuis@amsterdamumc.nl



We would also like to thank all the contributors of the Registry and look forward to collaborating with you in 2022!

The ESPN/ERA Registry: A pan-European dataset on pediatric kidney replacement therapy

By Enrico Vidal



Despite the staff shortage, thanks to an extraordinary commitment of our coordinator, Marjolein Bonthuis, and the vision of the previous scientific committee, chaired by Jérôme Harambat, the Registry is currently facing a very active period.

For most countries, data transfer agreements compliant with the updated European GDPR's requirement have been concluded, allowing for an almost pan-European geographical coverage. Moreover, under the umbrella of the ERA Registry, this year the ESPN/ERA Registry applied and obtained the ISO 27001 certification for information security. The entire process is of course demanding, and in the spring of 2022 the Registry will join the audit for the quality management system certification (ISO 9001).

Several studies have been planned or are already in the analysis phase. Henna Puusaari from Finland is currently leading an important study aimed at evaluating hard outcomes in children on KRT with a history of previous malignancy. Evgenia Preka is doing her PhD at the Academic Medical Center in Amsterdam, and she is working on a huge project about re-transplantation in patients transplanted during childhood. Fifty percent of all pediatric kidney transplant recipients are expected to undergo re-transplantation, but knowledge regarding outcomes is limited. One of the aims of our Registry is to identify best practice during childhood to improve long-term outcomes in adult life. In this regard, both the aforementioned and other planned projects are strategic, since they are based on new longitudinal analyses made possible thanks to a linkage of pediatric data with adult data from the ERA Registry.

A better understanding of CKD trajectories and patient outcomes could rely on the integration of KRT with pre-dialysis care data. The ERA Registry is currently recognizing the importance of obtaining knowledge on patients with advanced CKD in Europe and promotes the collaboration and the potential integration of information derived from the different national CKD pre-dialysis registries (Jager KJ et al., NDT 2021). In this regard, the pediatric panorama is less granular, but – in the near future – we should evaluate the opportunity for our Registry to become a platform for describing the complete pathway and outcomes of children with CKD.

There is a lot of exciting work to be done, with the real desire of joining an extraordinary collaborative and successful European effort.