

ESPN/ERA Registry Committee

Sevcan Bakkaloglu, Türkiye, ESPN/ERA Registry chair*

Julien Hogan, France, ESPN/ERA Registry vice-chair*

Dieter Haffner, Germany, ESPN secretary general

Jun Oh, Germany, ESPN treasurer

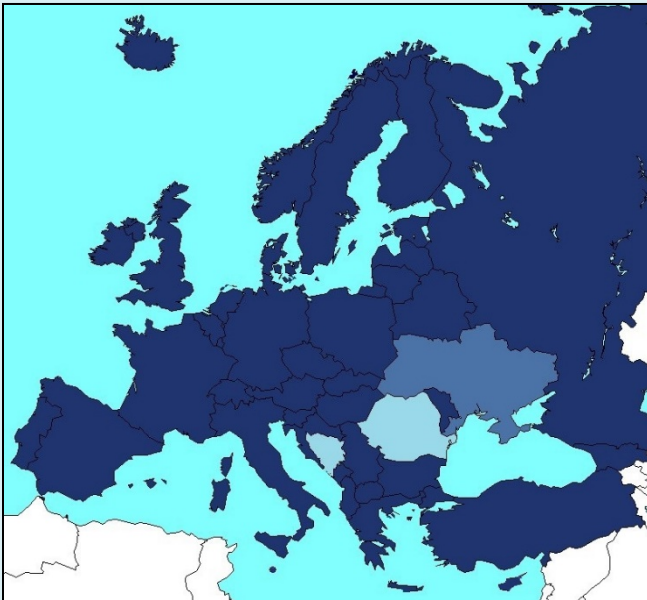
Vianda Stel, the Netherlands, ERA Registry director




Edoardo La Porta, Italy, Registry representative

Lucy Plumb, United Kingdom, Registry representative

Alberto Ortiz, Spain, ERA representative

*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 2024

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

Since September we have a new Registry Committee. Sevcan Bakkaloglu (Türkiye) succeeded Enrico Vidal (Italy) as chair of the Registry. Julien Hogan (France) has been elected as the new vice-chair and Edoardo la Porta (Italy) and Lucy Plumb (United Kingdom) are the new registry representatives. Please find below a piece from our previous and new chair.

With the help of all data contributors we were able to publish 2 papers in 2024 (please see below for further details). Several other papers are submitted or in preparation. Furthermore, several fellows were hosted. One of them, Henna Kajjansinkko, a paediatric nephrologist from Finland, worked on a project on KRT after cancer in children. You can read more about her project below.

The ESPN/ERA Registry would like to thank everyone for their continuous support!

Letter from the new Registry Chair

By Sevcan Bakkaloglu



Since its first launch in 2007, the productivity of the ESPN/ERA Registry has increased through the enormous effort of the team and European paediatric nephrologists. I will serve as the chair of the ESPN/ERA Registry for the 2024-2027 term.

It is a privilege to be a part of this team, and I thank previous chairs, vice-chairs, and the registry team, particularly Kitty Jager, Vianda Stel, and Marjolein Bonthuis.

During the next three years, one of our foremost priorities will be to create a European paediatric CKD registry and link it to the ESPN/ERA KRT Registry, then possibly merge it with the ERA Registry data. Besides ongoing studies, the CODIART study (Comparison of outcome parameters in pediatric dialysis patients with a prior history of allograft failure and kidney transplant naive ones), the first ESPN/ERA Registry Travel Grant winning project, will be realized. Most importantly, I would like to invite all ESPN members for their creative project proposals to be done in our registry.

I wish you all the best and a prosperous new year.

Longitudinal insights into KRT in children: Shaping the future through the ESPN/ERA Registry

By Enrico Vidal



In October 2024, my active involvement in the ESPN/ERA Registry came to a close, marking the end of a collaboration that started six years ago when I first took on the roles of vice-chair and later chair. In reality, my engagement with the registry's activities spans more than a

decade, beginning in 2013 with contributions to various research projects. During my tenure on the Registry Scientific Committee, I had the privilege of collaborating with colleagues of exceptional clinical, scientific, and ethical expertise, whose insights profoundly enriched both my personal and professional growth. Throughout this period, the registry's operations were impacted by the COVID-19 pandemic, which restricted researchers' access to the Amsterdam Medical Center, as well as by staffing shortages. The pandemic also prompted a policy shift in the Registry, as remote data analysis, which was previously prohibited, was eventually permitted. Marjolein Bonthuis, the Registry coordinator, provided invaluable support for ongoing studies while also managing critical institutional responsibilities, including data management, completion of data transfer agreements, and achieving ISO-27001 (Information Security) and ISO-9001 (Quality Management System) certification. Despite these challenges, the registry's scientific productivity remained strong, resulting in the publication of 20 scientific papers over six years.

Since January 2023, Marjolein has divided her time between the ERA Registry and the ESPN/ERA Registry. She has been joined in this effort by Iris Montez de Sousa, a full-time PhD student, with her main research focus on the epidemiology of KRT in young adults transitioning from paediatric to adult nephrology care. Marjolein's key role as a liaison between the two registries, along with Iris's enthusiasm for her research, are now driving the Registry's primary research agenda. This focus is increasingly directed towards longitudinal studies tracking clinical outcomes across the continuum of care, from childhood to adulthood. The availability of such longitudinal data has prompted discussions about incorporating pre-dialysis information into the Registry in the future. In this context, Sevcan Bakkaloglu (current Registry chair) has coordinated a survey that mapped six national registries already engaged in routine data collection for CKD stage 4-5 patients.

These registries could serve as a foundation for collaborative studies at the European level. Additionally, the establishment of a CKD registry linked to both the ESPN/ERA Registry and the ERA Registry's KRT data would offer significant benefits.

It would enable comprehensive monitoring of disease progression and development of early, effective strategies to manage modifiable risk factors, thereby preventing disease progression from childhood into adulthood. By bridging these data gaps, patient follow-up would become seamless, ultimately enhancing patient-centered outcomes.

The paediatric KRT registry itself remains critically important for several reasons. First, it represents the largest European dataset on paediatric KRT, encompassing data on ~30,000 patients over more than 15 consecutive years. This extensive dataset is essential for improving clinical practices, monitoring therapeutic evolution, and identifying epidemiological trends. Moreover, the Registry serves as an important identity tool for the ESPN, strengthening and promoting its visibility and influence in the global scientific community. Equally important, the Registry offers researchers, clinicians, and healthcare professionals invaluable opportunities for training in clinical epidemiology. It allows them to develop expertise in data analysis and conduct longitudinal studies. In this context, the recent opportunity - proposed by the ESPN - to apply for the ESPN/ERA Registry Travel Grant will support research projects, enabling the recipient to work on-site at the Registry in Amsterdam. Finally, the Registry acts as a critical bridge between paediatric and adult nephrology communities, fostering constructive dialogue, sharing of experiences, and dissemination of strategies and outcomes.

The newly established scientific committee is well-equipped to tackle the exciting challenges ahead. One of the most significant of these will be the integration of algorithms and artificial intelligence tools into data analysis, which has the potential to further elevate the Registry's utility and impact. I extend my heartfelt best wishes to the new committee members as they lead the Registry into the next chapter of its vital work. With their expertise, vision, and dedication, I am confident that they will bring fresh perspectives and innovative ideas to drive its continued success.

Publications 2024

Montez de Sousa IR, Bonhuis 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, Bakaloglu SA, Sørensen SS, Vila A, Ortiz A, Stel VS, Jager KJ.

Adult outcomes of childhood kidney replacement therapy in Europe from 2008 to 2019: an ERA Registry study.

Nephrol Dial Transplant. 2024 (Online ahead of print).

Kajjansinkko H, Bonhuis M, Jahnukainen K, Harambat J, Vidal E, Bakaloglu SA, Inward C, Sinha MD, Roperto RM, Kuehni CE, Biró E, Kwon T, Mota C, Ada, s B, Szczepańska M, Bienias 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.

Clinical outcomes of pediatric kidney replacement therapy after childhood cancer – ESPN/ERA Registry study.

Am J Transplant. 2024 (Online ahead of print.)

ESPN/ERA Registry

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Childhood cancer survivors' outcome on KRT

By Henna Kajjansinkko



Cancer survival has improved during the past decades leaving a growing group of childhood cancer survivors on kidney replacement therapy (KRT). Data on outcomes in this special patient group were very limited. Fortunately, the ESPN/ERA Registry gave us a great opportunity

for investigations. Two different groups can be noticed among childhood cancer survivors on KRT: young and very often nephrectomised Wilms patients and older childhood cancer survivors with a background of various cancer diagnoses plus an additional kidney disease reported as the reason for KRT. Therefore, we analysed these groups separately.

Mortality was significantly increased in both cancer groups compared to matched controls. But what is important, once transplanted, both patient and graft survival were similar to other kidney transplantation (KT) recipients. No cancer relapses were documented after the first KT. Most patients in one of the cancer groups suffered from growth retardation. Our follow-up time was not sufficient to manifest a late effect on hypertension or to really evaluate the incidence of second primary malignancies, although both cancer history and KT are known risk factors for these.

The good outcome after KT encourages us to transplant these children, when eligible, early enough to reduce their cardiovascular risk and enhance their growth potential.

The results of this study were recently published in American Journal of Transplantation. For more details, please see the publication list.

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.