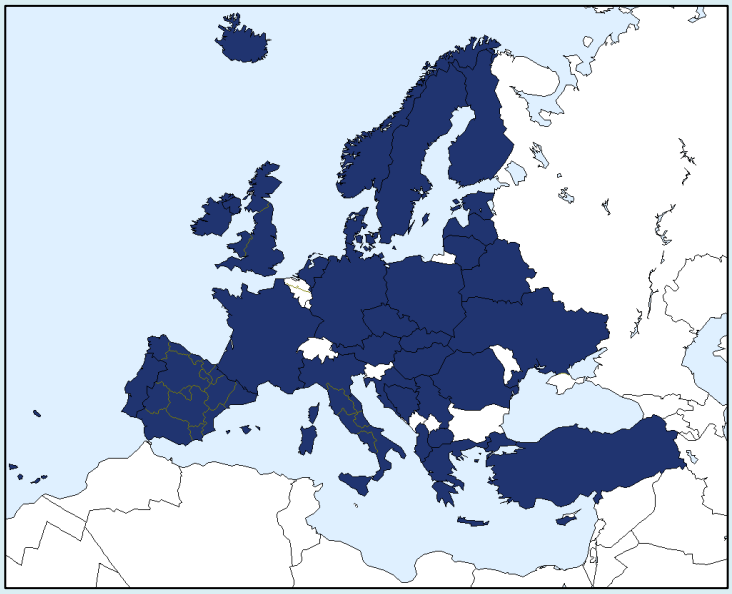
ESPN/ERA Registry

ESPN/ERA Registry https://www.espn-reg.org **ESPN** https://espn-online.org **ERA** https://www.era-online.org

ESPN/ERA Registry Committee

Sevcan Bakkaloglu, Türkiye, ESPN/ERA Registry chair*
Julien Hogan, France, ESPN/ERA Registry vice-chair*
Francesco Emma, Italy, 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



Countries contributing with 2023 data to the ESPN/ERA Registry.

Highlights of 2025

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 2025 (please see below for further details). Several other papers are submitted or in preparation.

But there is more!

An important part of the Registry's research activities originate from our successful internship programme. Evgenia Preka, a former fellow on the ESPN/ERA Registry, successfully defended her PhD thesis which included several Registry studies. Furthermore, as the winner of the first ESPN/ERA Registry Travel Grant, our Registry Chair, Sevcan Bakkaloglu, was in Amsterdam from August to October to work on an ESPN/ERA Registry project. More details on both projects can be found below.

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

PhD defence Evgenia Preka

On December 17th, Evgenia Preka (France) successfully defended her thesis entitled "Understanding the trajectories and related risk factors in European children on kidney replacement therapy (KRT) through epidemiological studies" at the University of Bordeaux. Her thesis, using data from both the ESPN/ERA Registry and the ERA Registry, provides valuable insights into the long-term outcomes of children initiating KRT in Europe. The work quantified the impact of dialysis timing, uncovered inequities in access to both first and repeat kidney transplantation, and she analyzed patient and graft survival after first, second, and third transplants. The findings can help inform clinical decision-making and guide health policy, ultimately contributing to better care, improved quality of life, and longer survival for children with kidney failure.

The ESPN/ERA Registry Travel Grant

By Sevcan Bakkaloglu

Since its establishment, the ESPN/ERA Registry has collected data from more than 30,000 children undergoing KRT across 38 countries. By generating publications based on robust epidemiological evidence, the Registry continues to play a crucial role in improving outcome parameters in pediatric patients. Its remarkable productivity has been made possible through the tremendous efforts of the Registry team and European pediatric nephrologists.

As the Chair of the ESPN/ERA Registry, it is a privilege to be part of such a dedicated and highly productive team. I would like to express my sincere gratitude to all colleagues who contribute their patients' data, as well as to the former chairs, vice-chairs, and the Registry team—particularly Vianda Stel, Marjolein Bonthuis, Iris Montez de Sousa, and Prof. Dr. Alberto Ortiz—for their unwavering commitment.

Over the past two years, a new initiative launched by ESPN—the ESPN/ERA Registry Travel Grant—has further expanded our scientific capacity. As the first-time Travel Grant winner, I visited the Registry in Amsterdam for 10 weeks working on a project on outcomes in pediatric dialysis patients with a history of allograft failure. Preliminary findings indicate that unknown underlying diagnoses and shorter prior graft survival are associated with poorer patient survival when returning to dialysis after graft failure. In contrast, male sex, age above 10 years, and initiating KRT with pre-emptive kidney transplantation emerged as the main predictors of accessing a second allograft. These results underscore the critical importance of establishing an accurate primary diagnosis and ensuring optimal care of the first graft to improve patient outcomes. In this context, my stay was memorable not only for the opportunity to work with the Registry team, to gain a deeper understanding of the core principles of epidemiological research, and to practice advanced statistical analysis, but also for witnessing Professor Kitty Jager's retirement ceremony and celebration, and for enjoying the beautiful city of Amsterdam.

The next Travel Grant was won by Vasiliki Karava from Greece and she will visit the Registry next year for her project, entitled "Determining optimal timing for pre-emptive kidney transplantation in pediatric patients". We look forward to the valuable insights this work will bring to the field. I would like to thank the ESPN President and the Board members for providing this opportunity on behalf of all current and future grant awardees and warmly invite all ESPN members to submit innovative project proposals that can be carried out using our Registry's rich dataset. Collaborative research is the foundation of our success, and your contributions are vital for advancing pediatric nephrology across Europe.

If you are interested in performing research on the ESPN/ERA Registry, or if you would like more information about the ESPN/ERA Registry, please contact us.

Publications 2025

Montez de Sousa IR, Bonthuis 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, Trujilo-Alemán S, Bakkaloglu 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. 2025;40(4):707-719. doi:10.1093/ndt/gfae189

Kaijansinkko H, Bonthuis M, Jahnukainen K, Harambat J, Vidal E, Bakkaloglu SA, Inward C, Sinha MD, Roperto RM, Kuehni CE, Biró E, Kwon T, Mota C, Ada,s B, Szczepańska M, Bieniaś 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. 2025;25(4):767-779. doi:10.1016/j.ajt.2024.11.002

Preka E, Bonthuis M, Marks SD, Kramer A, de Vries APJ, Sørensen SS, Bakkaloğlu SA, Bistrup C, Jahnukainen T, Rodriguez Arévalo OL, Buchwinkler L, Segelmark M, Sanchez JE, Arnol M, Ordóñez-Álvarez FA, de la Cerda-Ojeda F, Plumb LA, Methven S, Palsson R, Lundgren T, Ríos H, Ortiz A, Stel VS, Harambat J, Jager KJ.
Access to transplantation and re-transplantation in European kidney transplant candidates from childhood to adulthood: Long-term data from the ERA Registry.

Nephrol Dial Transplant 2025;40(8):1580-1589. doi: 10.1093/ndt/gfaf025

ESPN/ERA Registry

Marjolein Bonthuis (Registry coordinator)
Iris Montez de Sousa (PhD candidate)

Department of Medical Informatics
Amsterdam University Medical Centers, location AMC

Email: m.bonthuis@amsterdamumc.nl
i.r.montezdesousa@amsterdamumc.nl

european society for paediatric nephrology
espn

REGISTRY

Characteristics of kidney replacement therapy patients transferring from pediatric to adult nephrology care

By Iris Montez de Sousa

In December 2022, I joined the ESPN/ERA Registry as a PhD student, and it has been an enriching experience working with such a great team over the past 3 years. My research focuses on the transition from pediatric to adult nephrology care for adolescents and young adults on KRT.

The transition period, which spans several years, aims to prepare patients to manage their own care after transferring from pediatric to adult nephrology care. This is a challenging period for young patients. Kidney transplant recipients face an increased risk of graft loss between ages 17 and 24 years, likely due to incomplete brain maturation leading to non-adherence issues, while dialysis patients also struggle with non-adherence to medication, diet, and missed dialysis sessions.

We have previously described patient and graft outcomes in KRT patients aged 18 years in Europe (Montez de Sousa et al., NDT 2025). Kidney transplant recipients had a higher risk of graft loss compared to younger and older kidney transplant recipients, and a shorter life expectancy compared to healthy peers. Additionally, 18-year-olds on dialysis had an even shorter life expectancy. However, the actual age at transfer to adult care may vary based on factors like transition protocols, resource availability, patient readiness, and tools used for readiness assessment. At the ESPN/ERA Registry, we are currently studying clinical characteristics of KRT patients at time of transfer, and examining how these relate to transfer age. So far, we have found considerable country differences: median age at transfer ranged from 16 to 20 years, and the proportion of patients entering adult nephrology care with a functioning kidney graft varied between 38% and 90%. We also found that patients with glomerulonephritis or an unknown primary renal disease diagnosis (versus CAKUT), those with a longer KRT vintage (>5 years versus 1-5 years), and those transferring between the years 2000-2011 were more likely to transfer to adult care after their 18th birthday. These results may be valuable to both pediatric and adult nephrologists: pediatric nephrologists can assess the quality of their care, while adult nephrologists gain insight into the characteristics of patients transitioning from pediatric clinics and entering their care.

In 2024, we managed to link data from the ESPN/ERA Registry (pediatric patients) and ERA Registry (adult patients) for 12 countries. This provides a unique opportunity to analyze long-term outcomes of patients who initiated KRT in childhood. I look forward to continuing our research on this important topic.

Montez de Sousa, I. R., et al. Adult outcomes of childhood kidney replacement therapy in Europe from 2008 to 2019: an ERA Registry study. Nephrol Dial Transplant 2025;40(4):707-719. doi:10.1093/ndt/gfae189