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ESPN/ERA-EDTA Registry

Registry of the European Society for Paediatric Nephrology and the European Renal Association and European Dialysis and Transplantation Association



Leading European Nephrology

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

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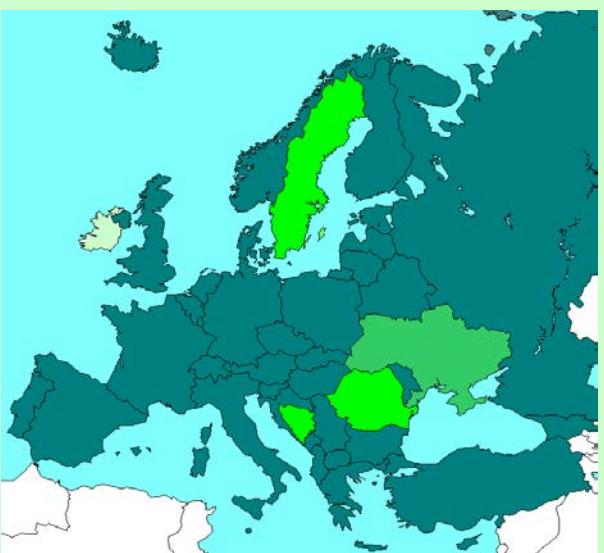
Scientific Committee

Jaap Grootenhoff, the Netherlands, chairman*
 Jerome Harambat, France, vice-chairman*
 Elena Levchenko, Belgium
 Dieter Haffner, Germany
 Kitty Jager, the Netherlands
 Constantinos Stefanidis, Greece
 Anna Bjerre, Norway
 Ziad Massy, France

*ESPN representatives on the ERA-EDTA Registry Committee

ESPN/ERA-EDTA Registry Staff

Marjolein Bonthuis (Registry coordinator)
 Nick Chesnaye (PhD candidate)



- 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
- Intend to contribute data in the near future

ESPN/ERA-EDTA Registry

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Highlights of 2016

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

With the help of all those who contributed in delivering data, we were able to publish 9 papers in 2016 (see list of publications for further details). Our major achievement was the acceptance of the paper on disparities in country mortality risk by *The Lancet*. Nick Chesnaye provides a summary of this work below. Several other papers have been submitted, and various other projects are ongoing.

Two guest researchers visited the Registry in 2016. In June, Evgenia Preka, a paediatrician from Brussels, worked on a project on eGFR at dialysis initiation and its association with outcomes, a project in collaboration with the ESPN Dialysis WG. Please find more information on this project below. Bram Smit, a medical student from Amsterdam, just completed his 16-week scientific internship on comorbidity data.

During the 2016 IPNA congress in Brazil several ESPN/ERA-EDTA Registry projects were presented. Please find more information below.

The ERA-EDTA supports Registry related activities of the association by providing research registry fellowships for young (< 40 years) nephrologists or nephrology researchers for the duration of 4-6 weeks. The deadline for applications is February 1st 2017. Please contact us if you are interested. We will be very happy to help you draft a proposal.

We would also like to thank all the contributors of the Registry and look forward to collaborating with you in 2017!

Seventeenth IPNA Congress

During the IPNA congress in Iguaçu, Brazil, the Registry was well represented.

Five research projects were presented orally. Fatos Yalcinkaya presented data on prune belly syndrome; data on Finnish type nephropathy were presented by Tuula Holtta, whereas Nick Chesnaye presented his work on donor-recipient age matching and graft survival, and Jérôme Harambat gave a presentation on post-transplant growth patterns. Furthermore, Marjolein Bonthuis presented data on vascular access as well as on the epidemiology of nutritional abnormalities in children with CKD.

Additionally, two posters were presented: one by Nick Chesnaye on mortality risk disparities and one by Lidwien Tjaden on racial variation in cardiovascular disease risk factors.



Publications 2016

Tjaden LA, Noordzij M, van Stralen KJ, Kuehni CE, Raes A, Cornelissen EA, O'Brien C, Papa-Christou F, Schaefer F, Groothoff JW, Jager KJ.

Racial disparities in access to and outcomes of kidney transplantation in children, adolescents and young adults: Results from the ESPN/ERA-EDTA Registry.
Am J Kidney Dis. 2016 Feb; 67(2):293-301.

Chesnaye NC, Schaefer F, Groothoff JW, Bonthuis M, Reusz G, Heaf JG, Lewis M, Maurer E, Paripović D, Zagodzon I, van Stralen KJ, Jager KJ.
Mortality risk in European children with end-stage renal disease on dialysis.
Kidney Int. 2016 Jun; 89(6): 1355-62.

Hogan J, Couchoud C, Bonthuis M, Groothoff JW, Jager KJ, Schaefer F, van Stralen KJ.

Gender disparities in access to pediatric renal transplantation in Europe: data from the ESPN/ERA-EDTA Registry.
Am J Transplant. 2016 Jul; 16(7):2097-105.

Harambat J, Bonthuis M, Groothoff JW, Schaefer F, Tizard EJ, Verrina E, van Stralen KJ, Jager KJ.
Lessons learned from the ESPN/ERA-EDTA Registry.
Pediatr Nephrol. 2016 Nov; 31(11):2055-64.

Mekahli D, van Stralen KJ, Bonthuis M, Jager KJ, Balat A, Benetti E, Godefroid N, Edvardsson VO, Heaf JG, Jankauskiene A, Kerecuk L, Marinova S, Puteo F, Seeman T, Zurowska A, Pirenne J, Schaefer F, Groothoff JW.

Kidney versus combined kidney and liver transplantation in children with autosomal recessive polycystic kidney disease: data from the ESPN/ERA-EDTA Registry.

Am J Kidney Dis. 2016 Nov; 68(5):782-788.

Hölttä T, Bonthuis M, van Stralen KJ, Bjerre A, Topaloglu R, Ozaltin F, Holmberg C, Harambat J, Jager KJ, Schaefer F, Groothoff JW.

Timing of renal replacement therapy does not influence survival and growth in children with congenital nephrotic syndrome caused by mutations in NPHS1- Data from the ESPN/ERA-EDTA Registry.
Pediatr Nephrol. 2016 Dec; 31(12):2317-2325.

Vidal E, van Stralen KJ, Chesnaye NC, Bonthuis M, Holmberg C, Zurowska A, Trivelli A, Eduardo Esteves Da Silva J, Herethelius M, Adams B, Bjerre A, Jankauskiene A, Miteva P, Emirova K, Bayazit AK, Mache JC, Sánchez-Moreno A, Harambat J, Groothoff JW, Jager KJ, Schaefer F, Verrina E.
Infants requiring maintenance dialysis: outcomes of hemodialysis and peritoneal dialysis.
Am J Kidney Dis. 2016 [ahead of print]

Chesnaye NC, Schaefer F, Bonthuis M, Holman R, Baiko S, Baskin E, Bjerre A, Cloarec S, Cornelissen EAM, Espinosa L, Heaf JG, Stone R, Shtiza D, Zagodzon I, Harambat J, Jager KJ, Groothoff JW, van Stralen KJ.

Mortality risk disparities in children receiving chronic renal replacement therapy for the treatment of end-stage renal disease across Europe. An ESPN/ERA-EDTA Registry analysis.

Accepted by *The Lancet*.

Tjaden LA, Jager KJ, Bonthuis M, Kuehni C, Lilien MR, Seeman T, Stefanidis CJ, Tse Y, Harambat J, Groothoff JW, Noordzij M.

Racial variation in cardiovascular disease risk factors among European children on renal replacement therapy- Results from the ESPN/ERA-EDTA Registry.
Accepted by *Nephrol Dial Transplant*.

Mortality risk disparities

By Nick Chesnaye

Our paper entitled "Mortality risk disparities in children treated for end-stage renal disease across Europe - An ESPN-ERA-EDTA Registry analysis" was recently accepted by *The Lancet*. In this paper, we demonstrate that considerable international variation exists in mortality rates across Europe in the paediatric RRT population, and that this was mostly attributable to an excess mortality risk for patients treated in some Eastern European countries. Most of this variation was explained by disparities in country public health expenditure, which seemed to limit the availability and quality of paediatric renal care services. Furthermore, differences in a country's ability to accept and successfully treat the youngest children, who are the most complex and costly to treat, formed an additional source of disparity within Europe. By exploring the magnitude of health-care inequalities, and by identifying both patient- and country-level determinants, we hope to increase the awareness amongst policy makers and in the paediatric nephrology community, and explore potential strategies to help reduce these disparities.



Dialysis timing and outcomes

By Evgenia Preka

In adult ESRD patients, early initiation of dialysis was not associated with an improvement in survival or clinical outcomes. However, data are lacking in children and it remains controversial in the paediatric population.

The ESPN/ERA-EDTA Registry provided me with the opportunity to work on this exciting project. We performed this study in order to (i) determine whether eGFR at start of dialysis influences different outcome parameters including mortality rate, access to transplantation, growth and control of CKD complications and (ii) determine the impact of a delayed referral to a paediatric nephrologist and a delayed initiation of RRT.

During this project, I gained important experience in handling epidemiological data, performing research with a huge database and interpreting my results. It was a very stimulating experience, not only because it was the first time working in that way (and not a purely clinical one), but also because I met very kind, intelligent and easy-going people to collaborate with on this project.

The next step is publishing our data and presenting them during international congresses.

Working for the Registry is an experience you won't regret!



Internships

The ESPN/ERA-EDTA Registry always welcomes individuals interested in performing an internship on the Registry. There are multiple projects available, but individuals with original ideas are very welcome. Please contact the registry staff if you would like to obtain more information about projects and funding for this.