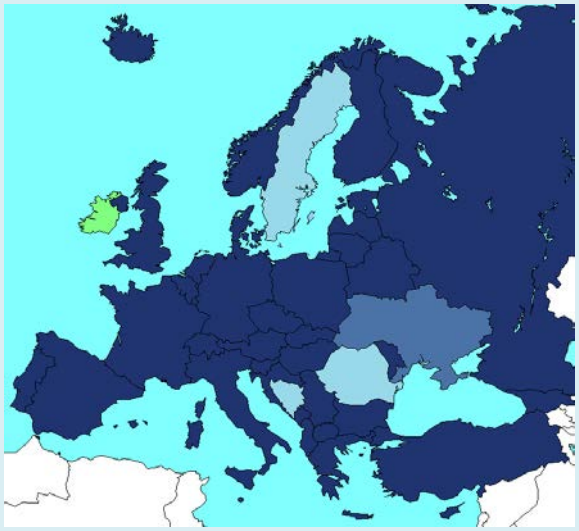
ESPN/ERA-EDTA Registry

ESPN http://espn-online.org/index.php **ESPN/ERA-EDTA Registry** http://www.espn-reg.org

ESPN/ERA-EDTA Registry Scientific Committee

Jaap Groothoff, the Netherlands, chairman*
Jérôme Harambat, France, vice-chairman*
Elena Levtchenko, 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



- 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 2017

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

2017 was a special year, because the Registry celebrated its 10th anniversary and we are very proud of all the achievements. Our success would not have been possible without your enthusiasm and great efforts and we look forward to continuing this fruitful collaboration in the future.

During the 50th ESPN congress in Glasgow several ESPN/ERA-EDTA Registry projects were presented. Please find more information below.
Six papers on various topics were published in different journals (see list of publications for further details) and many more are on their way.

For the first time, we provided data to the IPNA Global RRT Registry. Sophie Ploos van Amstel, the Registry coordinator, will provide more details on this cooperation below.

Furthermore, the second ESPN/ERA-EDTA Registry PhD thesis has successfully been defended by Nick Chesnaye.

Two guest researchers visited the Registry in 2017. In April, Liz Cuperus, a medical student from Leiden, started a project on transplantation outcomes. Please find more information on this project below. Michael Böhm, a paediatric nephrologist from Vienna, currently joins the Registry to work on a project on the minimum weight to transplant infants.
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 2018!

During the 50th ESPN congress in Glasgow, again a special symposium was dedicated to the Registry. During this symposium Lidwien Tjaden presented her work on ethnic disparities and outcomes in paediatric ESRD, Jérôme Harambat presented data on practice patterns and outcomes of paediatric kidney transplantation, while Marjolein Bonthuis showed data on recovery of renal function. Furthermore, Marjolein Bonthuis gave a presentation on anthropometry and outcomes in paediatric RRT and on the epidemiology of nutritional abnormalities in children with CKD.

IPNA Global RRT Registry

By Sophie Ploos van Amstel
IPNA Global RRT Registry coordinator

As demonstrated by various papers based on ESPN/ERA-EDTA Registry data, the incidence rates of RRT in children vary considerably between countries. This is not only the case in Europe but also in the rest of the world. As information from RRT registries offers the potential of a better understanding of the factors affecting this variation, the International Pediatric Nephrology Association (IPNA) recently initiated a global collaborative registry: "The IPNA Global RRT Registry" under the lead of Franz Schaefer.

Each country around the globe is invited to submit data on an annual basis. The core dataset contains patient level data regarding age, sex, primary renal disease, start date- and modality of RRT, as well as the date- and cause of death. The IPNA Global RRT Registry will use the information obtained to produce reports describing country specific RRT incidence and prevalence, modality choice and treatment outcomes including access to transplantation, graft- and patient survival. Detailed demographic and benchmarking figures will be generated to compare country specific pediatric RRT characteristics on a regional and global level. This information could then be leveraged to encourage governments and other funders to make an even greater effort to improve pediatric ESRD care.

The IPNA Global RRT Registry Committee is happy to inform you that the ESPN/ERA-EDTA Registry was the first international registry that agreed to collaborate with us and provided us with a complete dataset*. We would like to express our sincere gratitude and we look forward to a fruitful collaboration in the future.

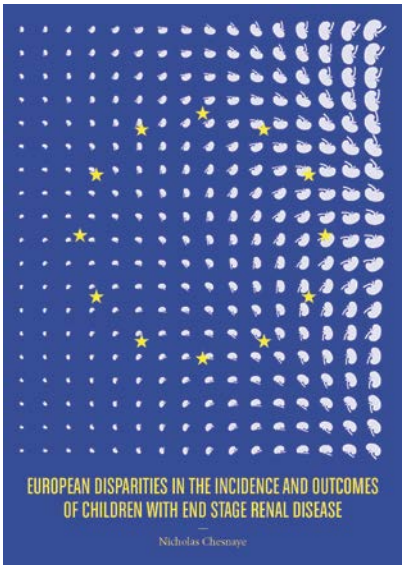
* For those countries that agreed on sharing their data

Thesis defence Nick Chesnaye

On December the 1st, Nick Chesnaye successfully defended his PhD thesis entitled "European disparities in the incidence and outcomes of children with end-stage renal disease".

His thesis aimed to reveal health inequalities and improve outcomes in the European paediatric RRT population. Geographical disparities in the quality and provision of RRT were found, and most disparities were attributable to an excess mortality risk and low incidence of paediatric RRT in several Eastern European countries. Both the incidence and mortality risk were strongly influenced by macroeconomic indicators, whereas patient characteristics had only marginal effects.

We hope that these results will increase awareness amongst policy makers and the paediatric nephrology community and provide the evidence in order to advocate policy change regarding resource allocation and clinical practice.



Publications 2017

Vidal E, van Stralen KJ, Chesnaye NC, Bonthuis M, Holmberg C, Zurowska A, Trivelli A, Eduardo Esteves Da Silva J, Herthelius 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. 2017 May;69(5):617-625.

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, Zagozdzon 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.
Lancet. 2017 May 27;389(10084):2128-2137.

Tjaden LA, Jager KJ, Bonthuis M, Kuehni C, Lilien MR, Seeman T, Stefanidis CJ, Tse Y, Harambat J, Groothoff JW, Noordzij M.
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Nephrol Dial Transplant. 2017 Nov 1;32(11):1908-1917.

Chesnaye NC, van Stralen KJ, Bonthuis M, Groothoff JW, Harambat J, Schaefer F, Canpolat N, Garnier A, Heaf J, de Jong H, Schwartz Sørenson S, Tönshoff B, Jager KJ.
The association of donor and recipient age with graft survival in paediatric renal transplant recipients in an ESPN/ERA-EDTA Registry Study.
Nephrol Dial Transplant. 2017 Nov 1;32(11):1949-1956.

Yalcinkaya F, Bonthuis M, Doganay Erdogan B, van Stralen KJ, Baiko S, Chehade H, Maxwell H, Montini G, Rönnholm K, Schwartz Sørenson S, Ulinksi T, Verrina E, Weber S, Harambat J, Schaefer F, Jager KJ, Groothoff JW.
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Pediatr Nephrol. 2018 Jan;33(1):117-124.

Chesnaye NC, van Stralen KJ, Bonthuis M, Harambat J, Groothoff JW, Jager KJ.
Survival in children requiring chronic renal replacement therapy.
Pediatr Nephrol. 2017 [Epub ahead of print].

Tx Outcomes

By Liz Cuperus
Medical student Leiden University

During the scientific internship for my medical studies, I got the opportunity to work on an ESPN/ERA-EDTA Registry project on paediatric kidney transplantation.

Previous studies have shown large disparities in paediatric kidney transplantation policies and practices between European countries. However, it remains unknown whether these disparities actually lead to different outcomes of kidney transplantation.
Therefore, the aim of my project is to determine the outcomes of paediatric kidney transplantation by studying the access to transplantation and the graft survival, and the disparities in these outcomes between the European countries.
Furthermore, in order to explain country differences in access to transplantation and graft survival, we studied the effect of several covariates (for instance, macro-economics, donor- and transplant characteristics, and patients' characteristics) on this country variation.

My internship at the ESPN/ERA-EDTA Registry is a great experience;
I learned a lot about epidemiological research, collaborated with very nice colleagues and even got the opportunity to go to Cyprus to follow the ERA-EDTA CME "Introductory course on Epidemiology".

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