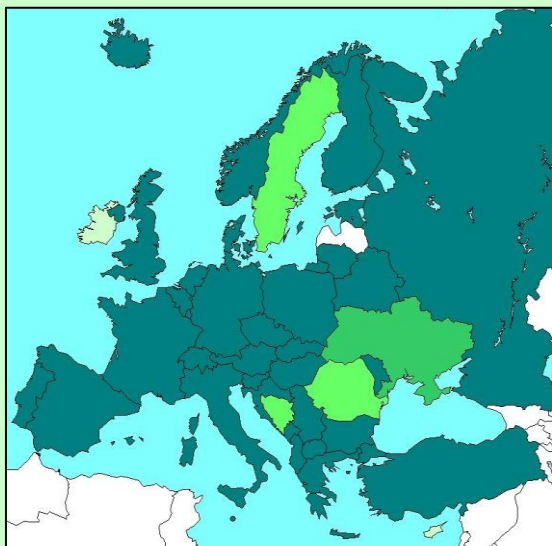





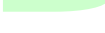
ESPN/ERA-EDTA Registry Scientific Committee

Franz Schaefer, Germany, chairman*
Jaap Groothoff, the Netherlands, vice-chairman*
Rosanna Coppo, Italy
Dieter Haffner, Germany
Jerome Harambat, France
Kitty Jager, the Netherlands
Constantinos Stefanidis, Greece
Christoph Wanner, Germany
* ESPN representatives on the ERA-EDTA Registry Committee

ESPN/ERA-EDTA Registry Staff

Marjolein Bonthuis (Registry coordinator)
Nick Chesnaye (PhD candidate)
Karlijn van Stralen (Advisor)



-  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 2014

With this newsletter we would like to update you on the latest activities of the ESPN/ERA-EDTA registry.

Because of the great efforts of all those contributing with data, we were able to publish 3 papers in 2014 (see list of publications for further details); several other papers have been submitted, and various other projects are ongoing.

Many different researchers visited the registry in 2014. In April, Beyza Doganay from Turkey visited the Registry to evaluate the clinical and demographic features of patients with Prune Belly Syndrome. Further, guest researcher Julien Hogan from France studied gender differences on and access to transplantation and found that females were less likely to receive a renal transplant (please see below for a more detailed description of his project). Next year various other researchers will visit the ESPN/ERA-EDTA Registry to perform an internship. We are very happy to announce that Dinara Galiyeva from Kazakhstan has received a research fellowship from the ERA-EDTA to perform an internship on the cardiovascular risk profile from March to May 2015.

During the ESPN congress in Porto there was a specific ESPN/ERA-EDTA Registry symposium in which many of the ongoing research projects were presented (more information below).

Furthermore, the first ESPN/ERA-EDTA Registry thesis has been defended and hopefully much many will follow in the future.

We thank all the contributors of the registry and look forward to collaborating more in 2015!

Happy Hellos and Hard Goodbyes

As you may have heard, after seven years of working for the Registry, Karlijn van Stralen decided to accept a position at EURODOPPS. Marjolein Bonthuis, who used to work as a PhD student on the Registry, has replaced her as the Registry coordinator as of the first of September. Fortunately, Karlijn will stay involved in the Registry as an advisor for the upcoming period, which will ensure its continuity as well as a smooth transition. We would like to thank Karlijn for the great enthusiasm and dedication she has shown towards the registry, and wish her the best of luck in her new position.



Karlijn van Stralen

Marjolein Bonthuis

Publications 2014

Chesnaye N, Bonthuis M, Schaefer F, Groohoff JW, Verrina E, Heaf JG, Jankauskiene A, Lukosiene V, Molchanova EA, Mota C, Peco-Antić A, Ratsch IM, Bjerre A, Roussinov DL, Sukalo A, Topaloglu R, van Hoeck K, Zagodzón I, Jager KJ, van Stralen KJ; the ESPN/ERA-EDTA registry.

Demographics of paediatric renal replacement therapy in Europe: a report of the ESPN/ERA-EDTA registry.

Pediatr Nephrol. (2014);29: 2403-10.

Wühl E, van Stralen KJ, Wanner C, Ariceta G, Heaf JG, Bjerre AK, Palsson R, Duneau G, Hoitsma AJ, Ravani P, Schaefer F, Jager KJ.

Renal replacement therapy for rare diseases affecting the kidney: an analysis of the ERA-EDTA Registry.

Nephrol Dial Transplant (2014);29:Suppl 4: iv1-8.

van Stralen KJ, Borzych-Dużalka D, Hataya H, Kennedy SE, Jager KJ, Verrina E, Inward C, Rönholm K, Vondrak K, Warady BA, Zurowska AM, Schaefer F, Cochat P; ESPN/ERA-EDTA registry; IPPN registry; ANZDATA registry; Japanese RRT registry.

Survival and clinical outcomes of children starting renal replacement therapy in the neonatal period.

Kidney Int.(2014);86: 168-74.

ESPN 47th Annual Scientific Meeting

In September, a successful edition of the ESPN/ERA-EDTA congress was held in Porto. Karlijn van Stralen presented data on the Progression of Renal Insufficiency in Children with CAKUT. During the Registry Symposium there were presentations on Disparities in RRT Incidence Across Europe (Nick Chesnaye), Paediatric RRT in ARPKD (Djalila Mekahli), Infant dialysis (Enrico Vidal), and Congenital nephrotic syndrome of the Finnish type (Tuulla Holtta).

Furthermore, two posters were presented: one on growth hormone policies (Maïke van Huis) and one on racial disparities in paediatric RRT (Lidwien Tjaden).

Thesis defence Marjolein Bonthuis

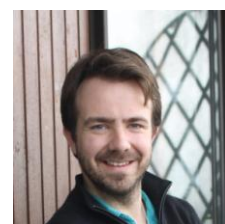
On September the 26th, Marjolein Bonthuis successfully defended her PhD thesis entitled 'Nutrition and growth in European children with end-stage renal disease'. The thesis includes papers on growth charts, growth hormone policies and final adult height, as well as BMI, and nutritional abnormalities frequently observed during childhood RRT, such as dyslipidaemia and disturbances in the mineral metabolism, showing the diversity of possible projects using Registry data.



Dr. Kitty Jager, Dr. Marjolein Bonthuis, Prof. Dr. Dieter Haffner, and Dr. Karlijn van Stralen after the defence

Why do girls with ESRD wait longer for transplantation than boys?

By Julian Hogan



Important inequalities between genders in access to transplantation have been demonstrated in adults. However, the presence of such a difference among children is still controversial.

The ESPN/ERA-EDTA registry provided the opportunity to validate this gender inequality in a large European population of children and to investigate its underlying causes.

Girls had a lower access to renal transplantation (HR 0.88, 95%CI 0.83-0.94) than boys, because of a 23% lower probability of receiving a pre-emptive transplant. A longer follow-up time prior to RRT was found in boys compared to girls despite a similar eGFR at first appointment with a nephrologist. We found a trend of faster progression towards ESRD in girls, which may participate in the shorter time available for pre-transplantation work-up. Finally, medical factors explained only 70% of the differences in pre-emptive transplantation rates, so that non-medical factors such as patient motivation, parental- and physician attitudes towards transplantation and organ donation may contribute to this inequality between genders.

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.