



Newsletter 2 / 2020

Dear colleagues,

this newsletter will update you on the recent publications from the CERTAIN Registry and on-going projects (see our website www.certain-registry.eu). 75 centres in 21 countries are currently contributing data from more than 2957 patients to CERTAIN. Many thanks to all of you for your contribution to previous and ongoing projects!

Yours, Burkhard Tönshoff and Lars Pape

Burkhard.Toenshoff@med.uni-heidelberg.de; Pape.Lars@mh-hannover.de

Save the date

The **CERTAIN workshop** will take place on **December 4 - 5, 2020** in Heidelberg. Because of the current COVID-19 pandemic we are planning a “hybrid” workshop, i.e. personal attendance for those who are able to travel and a virtual conference for those who prefer to stay at home. Of course, the pandemic situation may change; we are therefore also prepared to hold a virtual conference for all participants. Registration is open now under <http://certain-registry.eu/conference>; registration keyword: gpn44symposium. When registering please indicate whether you plan to participate personally or join us virtually.

New website design

Our website has received a new design. Visit <http://certain-registry.eu> and find information about ongoing research topic, publications, contributing centres, contact and support. In the “Publications” section you will also find a link to the PubMed CERTAIN Registry publication collection; all publications in one list ready to share or save.

Manuscripts recently published or submitted

1. Bernardor J, Schmitt CP, Oh J, Sellier-Leclerc AL, Büscher A, Dello Strologo L, Genc G, John U, Weitz M, Zirngibl M, Krupka K, Tönshoff B, Bacchetta J. **The use of cinacalcet after pediatric renal transplantation: an international CERTAIN Registry analysis.** *Pediatr Nephrol* 2020; 35:1707-1718.
2. Sugianto RI, Schmidt BMW, Memaran N, Duzova A, Topaloglu R, Seeman T, König S, Dello Strologo L, Murer L, Özçakar ZB, Bald M, Shenoy M, Buescher A, Hoyer PF, Pohl M, Billing H, Oh J, Staude H, Pohl M, Genc G, Klaus G, Alparlan C, Grenda R, Rubik J, Krupka K, Tönshoff B, Wühl E, Melk A. **Sex and age as determinants for high blood pressure in pediatric renal transplant recipients: a longitudinal analysis of the CERTAIN Registry.** *Pediatr Nephrol* 2020; 35(3):415-426.
3. Buder K, Zirngibl M, Bapistella S, Nadalin S, Tönshoff B, Weitz M, Members of the “Transplantation Working Group” of the European Society for Pediatric Nephrology (ESPN). **Current practice of antithrombotic prophylaxis in pediatric kidney transplantation—Results of an international survey on behalf of the European Society for Pediatric Nephrology.** *Pediatric Transplantation* 2020, e13799 (in press)
4. The publication by Antonia Bouts et al **European Society of Pediatric Nephrology survey on**

current practice regarding recurrent focal segmental glomerulosclerosis after pediatric kidney transplantation *Pediatr Transplant.* 2019 May;23(3):e13385 was the **most downloaded article in the year 2019** with 1058 number of accesses!

All publications from the CERTAIN Registry can be downloaded by registered users from the internal document platform of the CERTAIN website. On our public website <http://certain-registry.eu/publications> you will find a list of all publications with PubMed links.

Ongoing projects

Following projects are ongoing, and you are kindly invited to participate (detailed information with the respective analyses plans is available on the CERTAIN website www.certain-registry.eu in the internal document area "Analyses"):

1. Prevention of human papillomavirus (HPV) infection in paediatric kidney and liver transplant recipients and in paediatric patients with advanced chronic kidney disease: a prospective, observational multi-centre vaccine surveillance study (HPVaxResponse Study)

Britta Höcker, Tim Waterboer, Burkhard Tönshoff et al. Britta.Hoecker@med.uni-heidelberg.de

2. Antibody-mediated rejection in European paediatric renal transplant recipients: incidence, risk factors and outcome. Alexander Fichtner, Caner Süsal, Jan Becker, Britta Höcker, Lars Pape, Anette Melk, Stephen Marks, Luca dello Strologo, Kai Krupka, Burkhard Tönshoff et al. Alexander.Fichtner@med.uni-heidelberg.de

3. Long-term outcome after pediatric combined liver and kidney transplantation: A CERTAIN Registry analysis. Florian Brinkert, Jun Oh, Alexander Fichtner et al. f.brinkert@uke.de

4. Prevalence and influencing factors of hyperuricemia in pediatric renal transplant recipients – a retrospective CERTAIN analysis. Rasmus Ehren, Sandra Habbig, Lutz T. Weber et al. rasmus.ehren@uk-koeln.de

5. Outcome after paediatric kidney transplantation from very small donors: a retrospective observational matched cohort study. Raphael Schild, Jun Oh, Lars Pape, Burkhard Tönshoff et al. r.schild@uke.de (*Database closed*)

6. Hyperparathyroidism after paediatric RTx: risk factors, management strategies and association with longitudinal growth. Agnieszka Prytula et al. agnieszka.prytula@uzgent.be

7. Recurrence of nephrotic syndrome after pediatric kidney transplantation in Europe: risk factors, treatment and outcome. Antonia Bouts et al. a.h.bouts@amc.uva.nl

8. Arterial hypertension and cardiovascular comorbidity after renal transplantation – triggers, treatment and sequelae. Anette Melk, Elke Wühl et al. melk.anette@mh-hannover.de, elke.wuehl@med.uni-heidelberg.de

9. "Prospective longitudinal multi-center study evaluating modifiable barriers to accessing transplantation and transplant outcomes in children, in Europe", short title: "European Paediatric Access to Kidney Transplantation (EuPAKT)". Stephen D Marks, Ji Soo Kim, Kai Krupka and Burkhard Tönshoff stephen.marks@gosh.nhs.uk

10. Comparing modern molecular methods of assessing HLA immunogenicity to serology mismatching in paediatric kidney transplantation – a CERTAIN analysis. Jon Jin Kim, Alexander Fichtner, Caner Süsal et al. JonJin.Kim@nuh.nhs.uk

All ongoing and upcoming projects can be also found on our website under <http://certain-registry.eu/research>.

Registration for CERTAIN and Support

Not yet registered and wish to contribute to CERTAIN? Please register under <http://certain-registry.eu/register> or contact Kai Krupka directly: Kai.Krupka@med.uni-heidelberg.de.

Please address questions regarding data entry to our data quality manager Annette Mechler: Annette.Mechler@med.uni-heidelberg.de or look for our online tutorial on <http://certain-registry.eu/support>, the FAQ and help texts within the CERTAIN Registry application.