



Cooperative
European Paediatric
Renal
Transpl-
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Initiative



Newsletter 1 / 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). 73 centres in 20 countries are currently contributing data from more than 2800 patients to CERTAIN. Many thanks to all of you for your contribution to previous and ongoing projects!

The last CERTAIN workshop in Heidelberg on December 6 - 7, 2019 was attended by 104 participants from 14 countries! We are delighted about your enthusiasm and collaboration. Most of the presentations of this workshop are now available for registered users in the category "Presentations Heidelberg 2019" for download in PDF format from the CERTAIN website.

Yours, Burkhard Tönshoff and Lars Pape

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Save the date

The **German CERTAIN study group** will meet during the 51st Annual meeting of the Society for Paediatric Nephrology (GPN) in **Hamburg**, Germany, on **March 26, 2020** from 8 - 11 am. There will be a meeting of the CERTAIN study group/ESPN working group "Transplantation" during the upcoming ESPN congress in **Ljubljana**, Slovenia from **September 16-19, 2020**. The **next CERTAIN workshop** will take place on **December 4 - 5, 2020** again in Heidelberg.

CERTAIN-Nephropathology Survey

As discussed during the recent CERTAIN workshop in Heidelberg, we would like to add a more elaborate nephropathology module to CERTAIN in order to enable a closer involvement of your local nephropathologist and to facilitate collaborative research in this field. To this end, we ask you to forward this link https://www.surveymonkey.de/r/CERTAIN_Nephropath_Survey to the nephropathologist(s) collaborating with your centre. This survey should take max. 10 min to complete and is designed to establish firm contacts with the CERTAIN research community and to learn more about the pathologists' expectations from and potential contributions to CERTAIN. So please pass this on to your nephropathologist to fill in this survey. This survey is not meant to be taken by non-pathologists.

Manuscripts recently published or submitted

1. Sugianto R, Schmidt B, Memaran N, Duzova A, Seeman T, König S, Dello Strologo L, Murer L, Özçakar Z, Bald M, Shenoy M, Buescher A, Hoyer PF, Pohl M, Billing H, Oh J, Staude H, Pohl M, Genc G, Klaus G, Alparslan 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: 415–426.

2. Bernardor J, Schmitt CP, Oh J, Leclerc AL, Büscher A, Dello Strologo L, Genc G, John U, Weitz M, Zirngibl M, Krupka K, Tönshoff B, Bacchetta J. **Pilot study on the use of cinacalcet after pediatric renal transplantation: an international CERTAIN registry analysis**. Submitted.

All publications from the CERTAIN Registry can be downloaded by registered users from the document platform of the CERTAIN website.

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

6. Hyperparathyroidism after paediatric renal transplantation: 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

Projects being launched soon

1. 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

2. 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

3. Prospective longitudinal multi-center study evaluating modifiable barriers to accessing transplantation and transplant outcomes in children, in Europe. Stephen Marks, Ji Soo Kim et al. Stephen.Marks@gosh.nhs.uk

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.html>, the FAQ and help texts within the CERTAIN Registry application.