



Cooperative
European Paediatric
Renal
Transplant
Initiative



Newsletter 1 / 2021

Dear colleagues,

first of all, we wish you a successful and healthy year 2021!

This newsletter will update you on the recent publications from the CERTAIN Registry and on-going projects (see our website www.certain-registry.eu). 76 centres in 21 countries are currently contributing data from more than 3017 patients to CERTAIN. Many thanks to all of you for your contribution to previous and ongoing projects!

The first virtual CERTAIN workshop on December 4 - 5, 2020 was attended by 177 participants from 23 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 Virtual Workshop 2020" for download in PDF format from the CERTAIN website.

Yours, Burkhard Tönshoff and Lars Pape

Burkhard.Toenshoff@med.uni-heidelberg.de; Lars.Pape@uk-essen.de

Save the date

The next **virtual CERTAIN workshop** will take place on **May 8, 2021 from 9 am to 1 pm**. Registration will open soon under <http://certain-registry.eu/conference>; registration keyword: gpn45symposium.

The next CERTAIN workshop with hopefully personal presence is scheduled for December 3-4, 2021.

Data export optimization

The CERTAIN data export was optimized for the usage in statistical applications such as SPSS and SAS. More information on the data export file is given in the "How-to: Export and analyse data" help file which is available for download on our internal document platform under section "Instructions".

Laboratory import

Due to the improvements of the laboratory import, it is now possible to import data on trough levels of immunosuppressants. If you want to use this improvement or want to activate the laboratory import functionality for your centre, please contact Kai Krupka: Kai.Krupka@med.uni-heidelberg.de.

Manuscripts recently published or submitted

Weber LT, Tönshoff B, Grenda R, Bouts A, Topaloglu R, Gülhan B, Printza N, Awan A, Battelino N, Ehren R, Hoyer PF, Novljan G, Marks SD, Oh J, Prytula A, Seeman T, Sweeney C, Dello Strologo L, Pape L. **Clinical practice recommendations for recurrence of focal and segmental glomerulosclerosis/steroid-resistant nephrotic syndrome**. *Pediatr Transplant*. 2020 Dec 30:e13955. doi: 10.1111/petr.13955.

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: 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.

Organizational note: In January 2021 Kai Krupka is on parental leave. For account activation or in case of serious technical problems, please contact Aleksei Dudchenko: Aleksei.Dudchenko@med.uni-heidelberg.de