



Cooperative  
European Paediatric  
Renal  
Transpl-  
Ant  
Initiative



European  
Reference  
Network  
for rare or low prevalence  
complex diseases  
Network  
Kidney Diseases (ERKNet)

## Newsletter 3 / 2019

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](http://www.certain-registry.eu)). 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

During the upcoming **IPNA congress in Venice** from October 17-21, 2019, the **ESPN/CERTAIN Working group "Transplantation"** will meet on **Friday, October 18, from 11 am to 1 pm** in the "Sala Pasinetti" in the Palazzo del Cinema. The agenda will be distributed soon.

The first **CERTAIN Nephropathology workshop** will take place in **Rotterdam, The Netherlands**, from **November 15 - 16, 2019**. For further information, please contact Marian Clahsen-van Groningen, chair, local organizing committee: [m.clahsen-vangroningen@erasmusmc.nl](mailto:m.clahsen-vangroningen@erasmusmc.nl).

The **42<sup>th</sup> Symposium** of the **CERTAIN Study Group** will take place in **Heidelberg, December 6 - 7, 2019**. Online-registration has started under <http://certain-registry.eu/conference.html> (Registration keyword: gpn42symposium). Please book your hotel room yourself well in advance.

### Documentation and centres

66 centres in 19 countries are currently contributing data from more than 2631 patients to CERTAIN. We are very grateful for this excellent collaboration! For German centres in conjunction with the curatorship for home dialysis and transplantation (KfH), data entry has been facilitated by an interface between DISweb and CERTAIN. If you are using the KfH DISweb, please contact Kai Krupka [Kai.Krupka@med.uni-heidelberg.de](mailto:Kai.Krupka@med.uni-heidelberg.de) for activation of this interface.

### New patient information and consent form

The patient information and consent forms were revised according to the General Data Protection Regulation (GDPR) of the European Union. The new versions can be downloaded in English and German from the document platform in the CERTAIN Registry under "Patient information and consent forms"; an updated data privacy policy is available in English (<http://certain-registry.eu/privacy.html>) and in German ([http://certain-registry.eu/privacy\\_de.html](http://certain-registry.eu/privacy_de.html)).

### Manuscripts recently published or submitted

1. Höcker B, Schneble L, Murer L, Carraro A, Pape L, Kranz B, Oh J, Zirngibl M, Dello Strologo L, Büscher A, Weber LT, Awan A, Pohl M, Bald M, Printza N, Rusai K, Peruzzi L, Topaloglu R, Fichtner A, Krupka K, Köster L, Bruckner T, Schnitzler P, Hirsch H, Tönshoff B. **Epidemiology of and Risk Factors for BK Polyomavirus Replication and Nephropathy in Pediatric Renal Transplant Recipients: An International CERTAIN Registry Study**. *Transplantation* 2019 Jun; 103(6):1224-1233

2. Bouts A, Veltkamp F, Tönshoff B, Vivarelli M; Members of the Working Group "Transplantation", "Idiopathic Nephrotic Syndrome" of the European Society of Pediatric Nephrology. European Society of Pediatric Nephrology. **Survey on current practice regarding recurrent focal segmental glomerulosclerosis**

**after pediatric kidney transplantation.** *Pediatr Transplant.* 2019 Mar 1:e13385. doi: 10.1111/petr.13385.

3. 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*, 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](http://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. [Britta.Hoecker@med.uni-heidelberg.de](mailto: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. [Alexander.Fichtner@med.uni-heidelberg.de](mailto:Alexander.Fichtner@med.uni-heidelberg.de)

**3. Proteinuria as a non-invasive marker for renal allograft histology and graft failure in paediatric renal transplant recipients.** *Database closure: September 30, 2019*

Anja K. Büscher, Tomas Seeman, Stefanie Weber, Kai Krupka, Rainer Büscher, Burkhard Tönshoff, Peter F. Hoyer. [Anja.Buescher@uk-essen.de](mailto:Anja.Buescher@uk-essen.de)

**4. Transplantation in methylmalonic academia.** *Elisa Giammarioli, Friederike Hörster, Isabella Guzzo, Marco Spada, Mohan Shenoy, Nicholas J. A. Webb, Carlo Dionisi Vici, Burkhard Tönshoff, Luca Dello Strologo, luca.dellostrologo@opbg.net*

**5. Long-term outcome after pediatric combined liver and kidney transplantation: A CERTAIN Registry analysis.** *Database closure: September 30, 2019. Florian Brinkert, Jun Oh, Alexander Fichtner.*

[f.brinkert@uke.de](mailto:f.brinkert@uke.de)

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

**7. Cinacalcet after pediatric renal transplantation: a retrospective study in the CERTAIN Registry**

*Justine Bacchetta, Julie Bernador. Justine.bacchetta@chu-lyon.fr*

**8. Outcome after paediatric kidney transplantation from very small donors: a retrospective observational matched cohort study.** *Database closure: September 30, 2019*

*Raphael Schild, Jun Oh, Lars Pape, Burkhard Tönshoff. r.schild@uke.de*

## Projects being launched soon

**1. 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](mailto:a.h.bouts@amc.uva.nl)

**2. Hyperparathyroidism after paediatric renal transplantation: risk factors, management strategies and association with longitudinal growth.** Agnieszka Prytula et al. [agnieszka.prytula@uzgent.be](mailto:agnieszka.prytula@uzgent.be)

## 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](mailto: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](mailto: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.