



Cooperative  
European Paediatric  
Renal  
Transplant  
Initiative



## Newsletter 1 / 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)). Since many of the CERTAIN colleagues are also members of the ESPN working group “Transplantation” and/or of the ERKNet working group “Renal Transplantation”, we decided to issue one newsletter for all three initiatives to bundle the forces. Many thanks to all of you for your contribution to previous and ongoing projects!

Most of the presentations of the 40<sup>th</sup> Symposium of our study group in Heidelberg in December 2018 are now available for registered users in the category “Presentations Heidelberg 2018” for download in PDF format.

Yours, Burkhard Tönshoff and Lars Pape

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### Documentation and centres

More than 2434 patients from 66 centres in 19 countries are currently enrolled into the CERTAIN Registry. We are very grateful to all of you who contributed to this great success. Since the last newsletter four new centres joined the CERTAIN family: Barcelona (Spain), Izmir (Turkey), Ljubljana (Slovenia) and Paris (France). For German centres in conjunction with the curatorship for home dialysis and transplantation (KfH), data entry will soon be facilitated by an interface between DISweb and CERTAIN.

### 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”.

### New CERTAIN Registry design

With the recent CERTAIN Registry update, we revised the graphical user interface, which now gives a better overview, offers a cleaner design and is state-of-the-art. The data entry has remained the same and the workflows have not changed; you therefore will get used to it easily.

### Tutorial and training video

We have recorded a tutorial and training video for those who are not yet familiar with the CERTAIN Registry or want to refresh their knowledge how to enter data. The video is available on our website under <http://certain-registry.eu/support.html>.

### Save the date

The **50<sup>th</sup> Annual meeting** of the **Society for Paediatric Nephrology (GPN)** will take place in **Cologne, Germany, March 27 - 30, 2019**.

The **10<sup>th</sup> congress** of the **International Pediatric Transplant Association (IPTA)** will take place in **Vancouver, BC, Canada, May 4 – 7, 2019**.

## Manuscripts recently published

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 2018 Aug 20. [Epub ahead of print]
2. 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 HH, Tönshoff B. ***JC polyomavirus replication and associated disease in pediatric renal transplantation: An international CERTAIN Registry study.*** *Pediatr Nephrol.* 2018; 33:2343-2352
3. Kreuzer M, Prüfe J, Tönshoff B, Pape L. ***Survey on Management of Transition and Transfer From Pediatric- to Adult-based Care in Pediatric Kidney Transplant Recipients in Europe.*** *Transplant Direct* 2018; 4(7):e361
4. Kanzelmeyer NK, Zürbig P, Mischak H, Metzger J, Fichtner A, Ruszai KH, Seemann T, Hansen M, Wygoda S, Krupka K, Tönshoff B, Melk A, Pape L. ***Urinary proteomics to diagnose chronic active antibody-mediated rejection in pediatric kidney transplantation - a pilot study.*** *Transpl Int.* 2019; 32:28-37.

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. Immune Response of Paediatric Renal Transplant Recipients challenged by Sensitization, Vaccination or Non-Adherence: Cross-Sectional and Prospective Analyses of the International CERTAIN Registry Cohort (IMMRES)**

Lars Pape, Nele Kanzelmeyer, Anette Melk, Alexander Fichtner, Burkhard Tönshoff, Caner Süsal and members of the CERTAIN Research Network; [Kanzelmeyer.Nele@mh-hannover.de](mailto:Kanzelmeyer.Nele@mh-hannover.de)

### **2. 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, Julia Tabatabai, Michael Pawlita, Nick Webb, Burkhard Tönshoff Members of the CERTAIN Research Network; [Britta.Hoecker@med.uni-heidelberg.de](mailto:Britta.Hoecker@med.uni-heidelberg.de)

### **3. 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, Lennart Köster, Burkhard Tönshoff and members of the CERTAIN Research Network; [Alexander.Fichtner@med.uni-heidelberg.de](mailto:Alexander.Fichtner@med.uni-heidelberg.de)

### **4. Proteinuria as a non-invasive marker for renal allograft histology and graft failure in paediatric renal transplant recipients; Database closure deadline in March 2019**

Anja K. Büscher, Tomas Seeman, Stefanie Weber, Kai Krupka, Rainer Büscher, Burkhard Tönshoff, Peter F. Hoyer, and members of the CERTAIN Research Network; [Anja.Buescher@uk-essen.de](mailto:Anja.Buescher@uk-essen.de)

### **6. Transplantation in methylmalonic academia: An European survey.** *Elisa Giammarioli, Friederike Hörster, Isabella Guzzo, Marco Spada, Mohan Shenoy, Nicholas J. A. Webb, Carlo Dionisi Vici, Burkhard Tönshoff, Luca Dello Strologo, Members of the CERTAIN Research Network; [luca.dellostrologo@opbg.net](mailto:luca.dellostrologo@opbg.net)*

### **7. Long-term outcome after pediatric combined liver and kidney transplantation: A CERTAIN Registry analysis. End of recruitment deadline in March 2019**

Florian Brinkert, Jun Oh, Alexander Fichtner, Members of the CERTAIN Research Network; [f.brinkert@uke.de](mailto:f.brinkert@uke.de)

**8. Prevalence and influencing factors of hyperuricemia in pediatric renal transplant recipients – a retrospective CERTAIN analysis**

*Rasmus Ehren, Sandra Habbig, Lutz T. Weber and Members of the CERTAIN Research Network;  
rasmus.ehren@uk-koeln.de*

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

*Justine Bacchetta, Julie Bernador and Members of the CERTAIN Research Network;  
Justine.bacchetta@chu-lyon.fr*

**10. Outcome after paediatric kidney transplantation from very small donors: a retrospective observational matched cohort study.** *Raphael Schild, Jun Oh, Lars Pape, Burkhard Tönshoff and Members of the CERTAIN Research Network. r.schild@uke.de*

**Projects being launched soon**

**1. Incidence, treatment and outcome of recurrent steroid-resistant nephrotic syndrome after paediatric kidney transplantation in Europe.** *Antonia Bouts, Amsterdam and colleagues; a.h.bouts@amc.uva.nl*

**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).