

## **IMPLEMENTATION OF A NOVEL WEB-BASED REGISTRY FOR PEDIATRIC KIDNEY TRANSPLANTATION IN CENTRAL EUROPE - THE CERTAIN REGISTRY**

**Lukasz Plotnicki**[1,2], **Britta Hoecker**[1], **Christian Kohl**[3], **Burkhard Toenshoff**[1]

[1] Univ. Children's Hospital Heidelberg

[2] Med. Informatics, Univ. of Heidelberg

[3] Coord. Center for Clin. Studies, Univ. of Heidelberg

### **Purpose**

Long-term data collection for pediatric RTx recipients is crucial for clinical research, quality assurance and improved patient care, yet a proper registry in central Europe is lacking. Therefore, the German Paediatric Nephrology Association (GPN) decided in 2009 to initiate such a registry, which was named CERTAIN (Central European Paediatric Renal Transplant Initiative) Registry.

### **Method**

The registry has been developed as a distributed system using modern software technology. Data protection and security have been considered from the beginning. The developed concepts are based on the work of the German TMF – Technology, Methods and Infrastructure for Networked Medical Research organization ([www.tmf-ev.de](http://www.tmf-ev.de)). The registry's architecture and functionality assure the separation between personal and medical data on all levels incl. separate servers, strict data access policies and traffic encryption. The system offers a convenient web-application to access all registry functions. To minimize manual data input and workload in the participating centers, bidirectional data interchange with other systems, such as CTS, Eurotransplant and ESPN registry has been realized.

### **Results**

CERTAIN Registry is offering not only data entry functionality and, therefore, long-term data collection of pediatric RTx patients but also the possibility of patient record creation, real-time data analysis, patient & clinic benchmarking and automatic calculation of relevant clinical values. Thanks to the state of the art architecture and system modularity, it can be easily extended with new features. The registry is online since October 2010 ([www.certain-registry.eu](http://www.certain-registry.eu)) and accessible for all RTx centers, who wish to participate.

### **Conclusion**

The CERTAIN Registry provides a novel platform for clinical research in the field of pediatric RTx by use of modern IT methods, which will hopefully find a wide acceptance across central Europe. First registry reports are planned for mid-2011.