

## Cooperative European Paediatric Renal Transplant Initiative (CERTAIN) Registry – User Registration Form –

In order to use the CERTAIN Registry, you must at first apply for a CERTAIN Registry user account and agree to the privacy policy and service agreement. To apply for the account, please fill out this form and sign it. Then either sent it via mail, fax it to the given number or scan and email it to the registry headquarters:

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### User Details *(The attributes in bold type are mandatory.)*

Title: .....

**First name:** .....

**Last name:** .....

Birthdate: .....

**Phone number:** .....

Fax: .....

Mobile number: .....

**eMail:** .....

Website: .....

### User Role

- Study Nurse
- Clinician
- Supervising Clinician
- Steering Committee Member

### Center

**Name:** .....

.....

.....

### Address

**Name:** .....

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.....

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**Street address:** .....

**City:** .....

**Postcode:** .....

**Country:** .....

By signing this form you are accepting the CERTAIN Registry privacy policy and service agreement.

Date: .....

Signature: .....

## **Cooperative European Paediatric Renal Transplant Initiative (CERTAIN) Registry – Privacy policy and service agreement –**

The German Society for Paediatric Nephrology (GPN) is committed to protect your privacy and to develop technology that gives you powerful and safe online experience. Technical and organizational measures provide that we observe the laws of data protection. This agreement applies to the CERTAIN Registry internet portal and system (in the following referred to as ‘the CERTAIN Registry’) and governs data collection and usage. The CERTAIN Registry is stored and published on servers in Germany. By using the CERTAIN Registry, you should be aware of the practices as described in this statement.

### **Collection of Information**

#### *Utilization data*

Some information about your computer hardware and software which potentially is personally identifiable is automatically recorded by the CERTAIN Registry servers. On every request of a website of the CERTAIN Registry respective request information will be stored in a log file of the server. This is information your web browser transmits to our servers (your IP address/host name, browser type and version, operating system, requested URL, access time and date, web pages visited within the CERTAIN Registry and referring web site addresses).

This information will be stored anonymously and separated from personal data (e. g. registration data). Furthermore, the registry system collects user’s registry usage data (e. g. data input times, avg. session duration).

There will be no individual-related evaluation or single user profiles. The anonymous data is used by the CERTAIN Registry to provide general statistics regarding use of the CERTAIN Registry, for the operation of the service, to maintain quality of the service, for research purposes and to deliver customized content to users. Information will be published or provided to third parties only aggregated – this almost precludes identification of individuals.

#### *Use of Cookies*

The CERTAIN Registry uses cookies. A cookie is a text file that is placed on your hard disk by our web server. The purpose of a cookie is to improve navigation on websites and to recall your specific information on subsequent visits as well as to collect additional statistical information, e. g. which CERTAIN Registry services are the most popular. Cookies are uniquely assigned to your Computer and provide no personal identification. A Cookie can only be read by a web server in the domain that issued the cookie to you. Cookies cannot be used to run programs or deliver viruses to your computer.

You can also visit the CERTAIN Registry without accepting Cookies. If you choose to decline cookies, a mechanism called URL rewriting is used instead. URL rewriting means that a unique session identifier is added to every web address in order to enable a similar convenience as with the use of cookies.

*Notice:* Most web browsers automatically accept cookies, but you can usually modify your browser setting to decline cookies if you prefer.

#### *Personal Data*

Personal Data is useable to recognize your personal identity. This contains information like name, address, date of birth, e-mail address or phone number.

Visiting the general content of the CERTAIN Registry is possible without a personal registration. Everyone can visit this internet portal anonymously and view the information inside.

## Registration

For the use of the actual CERTAIN Registry system a registration is needed before. For registration users should contact the respective system administrator.

For your own security we recommend to store your password at a safe place. Please inform us immediately about lost or stolen passwords.

*Notice:* For security reasons you will be forced to change your personal password at least every six months.

## Security and Confidentiality

When personal information is transmitted to the CERTAIN Registry, it is protected through the use of encryption, such as the Secure Socket Layer (SSL) protocol.

For the CERTAIN Registry all technical and organizational measures will be implemented to secure personal information from unauthorized access, use or disclosure. Access to personal user data is granted only to authorized GPN employees respectively authorized service providers for their official duties. Violating the principles of security and confidentiality as part of this agreement will result in disciplinary measures.

*Notice:* If you directly disclose personally identifiable information or personally sensitive data through public message boards, wikis, e-mail-lists etc. this information may be collected and used by others.

## Distribution of Personal Data

Your personal data is used in the GPN CERTAIN Registry exclusively. No Information will be provided to third parties without your agreement.

## Changing or Deleting of Data

Information about registered users will be stored in the CERTAIN Registry servers as long as they are registered.

Of course you can edit all your personal information at any time. To delete your account please contact the system administrator. Then your account will be inactivated, however, your data will still be stored in the system in the CERTAIN Registry to fulfill audit trial requirements.

## Right of Information

You can require information about your personal data stored on CERTAIN Registry servers at any time (please contact the system administrator [kai.krupka\[at\]med.uni-heidelberg.de](mailto:kai.krupka[at]med.uni-heidelberg.de)).

## Changes to this Statement

The GPN will occasionally update this agreement to reflect amendments and user feedback. GPN encourages you to periodically review this statement to be informed of how GPN is protecting your information.

## Information via E-Mail

Registered users will receive important information from the GPN about the CERTAIN Registry and appointments by e-mail. By registering for CERTAIN Registry you accept to receive such e-mails.

## Contact

The GPN welcomes your questions or complaints about data protection and collecting and using data in the context of CERTAIN Registry, their conformity with this statement of privacy as well as your comments and suggestions regarding these points. Please mail respective topics to the system administrator ([kai.krupka\[at\]med.uni-heidelberg.de](mailto:kai.krupka[at]med.uni-heidelberg.de)).