

## Information on data processing and data protection

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**Dear patient, dear prospective customers.**

On this page we would like to inform you about data processing and data protection in the Center for Rare Diseases (ZSE). You must take note of this information before you pass on documents or data to our contact point. Participating institutions

### **The ZSE is a facility of the Ulm University Hospital**

The ZSE contact point is located at the Clinic for Pediatric and Adolescent Medicine at the Ulm University Clinic. The cooperation between hospital and university facilities in medical areas always takes place as Ulm University Medical Center. The clinic remains the responsible body in terms of data protection law.

Further members of the ZSE are clinical-theoretical institutes of the university (e.g. the Institute for Human Genetics), clinical departments of the Bundeswehr Hospital Ulm, the University and Rehabilitation Clinics Ulm (RKU) and the Günzburg District Hospital (BKH). A list of all members can be found on our website or in the flyer that we have handed out / sent to you.

### **Storage period**

Your data will be sent to the contact point no later than the 6th year after the last processing. Insofar as your data becomes part of your patient file in the further course of your care at the University Hospital, the statutory retention periods of up to 30 years after the treatment apply for medical documentation.

### **Information flows**

The contact point (employees of the university hospital) receives your data. It stores contact details and measures taken (such as the experts involved). Based on your request and the data and documents provided, the contact point selects selected medical experts for the diagnostic and therapeutic analysis of the case. These experts receive copies of the documents sent to us by post (in accordance with Section 46 (1) No. 1 or No. 3b of the Baden-Württemberg State Hospital Act), which you leave to us or which we request from the treating physician after the patient has released him from confidentiality. If the expert considers an examination and / or therapy in his facility to be expedient, he will keep the documents for further work. Otherwise he will send them back to the contact point or destroy them in accordance with data protection regulations.

### **Transmission of data**

When using electronic transmission channels (e-mail, fax) there are fundamental risks (e.g. due to misdirection). In the event that the initial request is made by e-mail or fax, we assume your implicit consent to be able to use these transmission channels. Please inform us if you do not want this. Alternatives are then sending the mail and making phone calls.

### Earmarking, rights, contacts

We process your data exclusively for the purposes mentioned on the basis of your consent and release from confidentiality. Insofar as your data is processed further in the supply department at the University Hospital, the data protection information applies for this. Corresponding and further information on data protection (your rights, contacts) can be found in the University Hospital's data protection declaration at [www.uniklinik-ulm.de](http://www.uniklinik-ulm.de)

### **Thank you for your attention.**

Please confirm that you have read this information and that you agree to the procedure on the "Consent and release from confidentiality" form.

### **Your team at the contact point of the Center for Rare Diseases**