

## Information on data processing and data protection

Last updated 11.2016

### Dear patient, dear reader,

This page provides information on data processing and data protection at the Centre for Rare Diseases (ZSE). You must take note of this information before you pass on documents or data to our contact point.

### Involved institutions

The ZSE is an institution of University Medical Centre Ulm. The Neurophysiology department of Ulm University maintains the ZSE contact point on behalf of the University Medical Centre. The collaboration of Medical Centre and University institutions in medical areas is always carried out as University Medicine. The responsibility concerning data protection, however, remains with the University Medical Centre.

Other members of the ZSE are the clinical-theoretical institutes of the University (e.g. the Institute of Human Genetics), clinical departments of the Bundeswehrkrankenhaus (military hospital), the Rehabilitation Hospital Um (RKU) and the Bezirkskrankenhaus Günzburg (district hospital). A list of all members can be found on our homepage or in the flyer that is available on request.

### Information flow

The contact point (employees of the University) receives your data. They save your contact details as well as initiated measures (e.g. involved experts). Your data are kept for a maximum of 6 years after the last processing through the contact point and will be deleted afterwards.

The contact point selects suitable medical experts for the diagnostic and therapeutic analysis of the case based on your enquiry and provided data. These experts receive (in accordance with § 46 para.1 no.1 and no. 3b Landeskrankenhausgesetz Baden-Württemberg [state law on hospitals]) via mail copies of the documents that you provide or that we request from treating doctors upon authorisation for the release of medical information by the patient.

The experts will keep these documents for further reference, if they deem an examination and/or therapy in their institution helpful. In any other case, they return them to the contact point or destroy them in accordance with data protection requirements.

### Transfer of data

Electronic ways of transfer (email, fax) generally bear certain risks (e.g. misrouting). If the first enquiry comes in via email or fax, we assume your implicit consent to the use of these means of transfer. Please inform us if you object. Alternatives are mail order and phone calls.

### Thank you for your attention.

Please confirm notice of this information and your consent to the approach on the form 'Declaration of consent and authorisation for the release of medical information'.

### Your team of the contact point of the Centre for Rare Diseases