

Dear patient, Dear colleague,

we would like to give you a brief information and assistance on the procedure at the Center for Rare Diseases in Ulm in advance.

**The ZSE Ulm only sifts through medical inquiries. Please contact your treating GP or specialist.**

#### Required documents at the Center for Rare Diseases Ulm

The following documents must be submitted to us by post, fax or email

- Medical inquiry (to be filled out by the general practitioner or specialist)
- Registration form for referring physicians (to be completed by the general practitioner or specialist)
- Medical history questionnaire (to be filled out by the patient with the help of their general practitioner or specialist)
- Family history chart
- Copies of all relevant medical preliminary findings (somatic and psychosomatic /psychiatric findings)
- Medication plan
- Relevant imaging on CD
- Meaningful photo material on externally visible changes in the skin/hair/mucous membranes/eyes/face, hands, feet, ears
- Consent to release from the duty of confidentiality

**Please only send us copies as the documents cannot be returned**

**Please take note of the "Information on data protection" before sending.**

Please send your request by post, e-mail (file size max. 3 MB) or by fax to the following address:

**Zentrum für Seltene Erkrankungen Ulm**  
**Universitätsklinikum Ulm | c/o Klinik für Kinder- und Jugendmedizin**  
**ZSE Kontaktstelle**  
**Eythstraße 24**  
**89075 Ulm**  
**E-Mail: [zse@uniklinik-ulm.de](mailto:zse@uniklinik-ulm.de)**  
**Tel. (+49) 731 500-57080**  
**Fax: (+49) 731 500-57058**  
**[www.uniklinik-ulm.de/zentrum-fuer-seltene-erkrankungen](http://www.uniklinik-ulm.de/zentrum-fuer-seltene-erkrankungen)**

**The telephone office hours of the contact point are:**

Tuesday from 12 a.m. to 2 p.m.

Thursday from 9 a.m. to 11 a.m.

*Due to the extensive processing, waiting times of several weeks can arise, for which we ask for your understanding.*

**We ask you not to put staples and paper clips on the documents!**

When sending by email, limit the documents to a PDF of max. 3 MB.

We ask for your understanding that we can only review complete documents. If the required documents are incomplete or not sorted chronologically as described above (findings), we cannot process your request!

### **The review and decision of your case.**

1. You do not need a referral to contact the center, and the request does not entail any costs for you.
2. The receipt of your request will always be confirmed in writing.
3. Our group of experts sifts through your documents. Please note that this screening will take the necessary time. We ask for your patience.
4. You will always receive a letter of recommendation in writing.
5. The center does not have a direct ambulance. If necessary, we recommend a presentation in one of our specialist disciplines / departments.

If you have any questions, please do not hesitate to contact us by email at [zse@uniklinik-ulm.de](mailto:zse@uniklinik-ulm.de).

Many Thanks!

Your team from ZSE Ulm