

Dear patient,

We would like to provide you with some brief information and assistance with the process at the Centre for Rare Diseases (ZSE) in Ulm.

The ZSE is part of the University Medical Centre Ulm and the Medical Faculty of Ulm University. It comprises a consortium of numerous clinics and institutes that concern themselves with rare diseases. **The ZSE Ulm does not offer consultation hours and treatment appointments itself. We refer to experts at our Centre.** Patients and their relatives or referring doctors can contact us with their request via our contact point.

Your enquiry at the Centre for Rare Diseases (ZSE) Ulm

1. To clarify your enquiry, the following points are crucial: Have you already submitted an enquiry to another centre for rare diseases?
 - If yes: Please wait for their response to your enquiry.
2. Is there a centre that might be closer to your home than the ZSE Ulm?
 - If yes: We recommend that you submit an enquiry to this expert centre first.
3. Does your treating GP and/or specialist doctor recommend the enquiry at the Centre for Rare Diseases?
 - If yes: Please provide us through your GP and/or specialist doctor **copies of relevant preliminary findings (medical reports, lab results etc.) that might relate to a rare disease only.** Please **do not** provide additional documents like medical histories.

Please do not staple the documents or hold them together with paper clips!

If you send your documents via email, please keep it at one PDF file with a maximum size of 5MB.

4. The ZSE website www.uni-ulm.de/en/zse provides an overview of the specialisations at the Centre for Rare Diseases, to be found under 'Treated diseases'. This is a good starting point to inform yourself before you submit your enquiry to the ZSE.

Required documents

Please fill out the questionnaire as far and as thoroughly as possible, with all relevant details of your symptoms and medical history. Please use this questionnaire *only* and *no other files*. If further documents are required, we will request them from you.

You can download the interactive questionnaire from our website. We furthermore require the signed authorisation for the release of medical information. Please take note of the ZSE's privacy policy. *We are unable to process your enquiry if we do not have all required documents.*

Please send your enquiry by mail, email (max. file size 5MB) or 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, Germany
Email: zse.info@uniklinik-ulm.de
Phone (+49) 731 500-57080
Fax: +49 731 500-57058
www.uni-ulm.de/en/zse

You can reach the ZSE contact point by phone Monday to Friday from 8 a.m. till 12 p.m.

Review of your case and decision

1. We will confirm the receipt of your enquiry in writing.
2. Our experts will review your documents. Please note that this review might take some time. We thank you for your patience.
3. You will receive a letter of confirmation.
4. You do not need a referral to submit an enquiry to the ZSE and this service comes free of charge.