ZSE ULM
ZENTRUM FÜR SELTENE ERKRANKUNGEN
UNIVERSITÄTSMEDIZIN ULM
NETZWERK BADEN-WÜRTTEMBERG

UNIVERSITÄTS KLINIKUM ulm

Reset form | This form can be filled out on the screen | Print form

Enquiry form Centre for Rare Diseases (ZSE) Ulm
Fields marked with * are mandatory

_____
ZSE Ulm-Nr. intern

Personal details: **(*Required fields)**

1. Academic degree _____

2. Surname/ first name*: _____

3. Date of birth * _____ Your gender ☐ m ☐ f ☐ divers

4. Adress* _____

5. Phone number* _____

6. E-Mail
(if available) _____

7. Insurance status * ☐ Statutory health insurance _____
☐ privat _____

8. Marital status _____

9. Number of children _____

10. Nationality _____

11. Current weight * _____

12. Current size * _____

13. If you are not the patient, how do you relate to the patient?

☐ Relatives (life partner, relatives, etc.) ☐ Doctor
☐ Other _____

14. If not a patient, please provide contact details: (address, telephone, e-mail) _____

15. Employment status
☐ Full-time or fully incapacitated ☐ Unemployed / permanently disabled
☐ Pensioner in early retirement ☐ Housewife / househusband
☐ Others: _____

16. Profession _____

Your reason for contacting the ZSE Ulm?

17. What is the main reason for you contacting the ZSE Ulm?

Diagnosis Information on a disease ☐
search for expert ☐
second opinion ☐
Other reason ☐ in fact _____

18. Has the attending physician expressed a specific suspicion of a rare disease?

☐ No ☐ Yes, suspicion of: _____

19. Have you ever been diagnosed with a rare disease?

☐ No ☐ Yes, namely: _____

20. Please state your exact request:

_____

_____

_____

_____

_____

_____

_____

_____

21. How did you find out about ZSE Ulm?

doctor	☐	Family / friends	☐	Others	☐ _____
Internet	☐	Print media	☐		
Self-help / Patient organization	☐	ZSE homepage	☐		

Current complaints

22. Please state the main current complaints.
How strong are these on a scale from 1 (low) - 5 (very strong)?

1. Main complaint _____ from age _____
☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ varies greatly

2. Main complaint _____ from age _____
☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ varies greatly

3. Main complaint _____ from age _____
☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ varies greatly

Course of disease

23. At what age did the symptoms start?

Discomfort since birth ☐
First complaints from age: _____

24. When was the last time you were abroad, especially before the onset of the illness, and where?

_____

25. Please mark all of your affected organ systems:

Eye	☐	Heart	☐	Adrenal gland	☐
pancreas	☐	Endocrine system	☐	Annoy	☐
blood formation	☐	immune system	☐	Kidneys	☐
Intestines	☐	Bones	☐	Liver	☐
Bile	☐	Cycle	☐	Ears	☐
Brain	☐	Lung	☐	Thyroid	☐
Joints	☐	Stomach	☐	Digestive system	☐
genital organs	☐	Spleen	☐	Teeth	☐
Neck	☐	Muscles	☐		
Skin	☐	Nose	☐		

Others _____

26. With which complaints did the disease begin (up to 3 complaints in order of importance)

1. Complaint _____ Age at the beginning _____

2. Complaint _____ Age at the beginning _____

3. Complaint _____ Age at the beginning _____

27. Are there any other complaints?
How strong are these on a scale from 1 (low) to 5 (very strong)?

1. Complaint _____
from age: _____
☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ varies greatly

2. Complaint _____
from age: _____
☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ varies greatly

3. Complaint _____
from age: _____
☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ varies greatly

28. Did your family / blood relatives experience similar symptoms? (Multiple answers possible)

No ☐
No statement possible ☐

Yes, namely: Children ☐ Parents ☐
Grandparents ☐ Uncle /aunt ☐
Siblings ☐
Others _____

*Family member	Complaint 1	Complaint 2	Complaint 3

* (Please indicate if maternal or paternal, e.g. aunt maternal.)

Diagnosis

29. Have diagnoses already been made for the current complaints?

Yes ☐ No ☐

in fact: _____

Diagnosis (Doctor / clinic) _____ Diagnosis on (Month /year) _____

30. Can this diagnosis be regarded as certain?

No ☐
Yes ☐

The suspected diagnosis is: _____

31. Are there any doubts about this diagnosis?

No ☐
Yes ☐

32. Who raised doubts about the diagnosis?

From my own family doctor ☐
Specialist ☐
Family ☐
Other: _____

33. For what reasons were doubts about the diagnosis expressed?

_____

_____

34. Has the diagnosis changed in the meantime?

No ☐ Earlier diagnosis
Yes ☐ was: _____

35. Regardless of the main complaints, are there other diagnoses?

No ☐ Diagnosis 1 _____
Yes, that is ☐ Diagnosis 2 _____
Diagnosis 3 _____
Diagnosis 4 _____

36. Do you have allergies?

_____

37. Do you suffer from intolerances?

_____

38. Do you have any special eating habits? (meatless or vegan food)

_____

39. Do you have pets? Yes ☐ Yes, that is _____ No ☐

Diagnostic route

40. When (month / year) were the following facilities visited for the first time to clarify the current complaints?

General practitioner / family doctor (name): _____ visited on (month / year): _____

Specialist (with specialization): _____ visited on (month / year): _____

Regional hospital (name): _____ visited on (month / year): _____

University hospital (name) _____ visited on (month / year): _____

41. Have you already contacted other centers for rare diseases (ZSE)?

No ☐ Yes ☐

Name of the center: _____ visited on (month / year): _____

41. Have you already been to the Ulm University Hospital because of the current complaints?

No ☐ Yes ☐
Name of department (possibly doctor) _____ visited on (month / year): _____

Name of clinic (possibly doctor) _____ visited on (month / year): _____

43. Which other doctors were already involved in clearing up the current complaints?

Allergist	☐	Homoeopath	☐	Psychiatrist	☐
General practitioners	☐	Human geneticist	☐	Psychologist	☐
Ophthalmologist	☐	Immunologist	☐	Psychosomatic	☐
Chiropractor	☐	Internist	☐	Radiologist/ Nuclear medic	☐
Surgeon	☐	Cardiologist	☐	Rheumatologist	☐
Diabetologist	☐	Pediatrician	☐	Paintherapist	☐
Endocrinologist	☐	Pulmonologist	☐	Environmental medic	☐
Gynecologist	☐	Neurosurgeon	☐	Urologist	☐
Gastroenterologist	☐	Neurologist	☐	Dentist	☐
Vascular doctor	☐	Kidney doctor	☐		
Haematologist	☐	Oncologist	☐		
Dermatologist	☐	Orthopedist	☐		
ENT doctor	☐	Pathologist	☐		

Others _____

44. Have you contacted additional sources to confirm the current diagnosis?

No	☐	Yes	☐
		Internet	☐
		Self-help group / patient organization	☐
		Other:	☐ _____

45. Please tick whether the following symptoms or events apply to you:

Joint stiffness in the morning	☐ No	☐ Yes, that is		Minutes
tick bite	☐ No	☐ Yes, in the year		
		☐ with rash		
		☐ with antibiotic therapy		
Night's rest is through	☐ No	☐ Rare	☐ never	
Disturbed pain				
Back pain	☐ No	☐ Yes	☐ at night, too	
Back pain with	☐ No	☐ left	☐ right	
Radiance in one leg				
Back pain with	☐ No	☐ left	☐ right	
Radiance in one arm				
Painful white, connecting	☐ No	☐ left	☐ right	
of the hands turning blue in the cold				
Inflammation / redness of the eyes	☐ No	☐ Yes, since		(Year)
Dryness of the eyes / mucous	☐ No	☐ Yes, since		(Year)
skins (also mouth, genital area				
Other changes to the skin	☐ No	☐ Yes, since		(Year)
and mucous membranes (also mouth, genital area)				
Painful urination	☐ No	☐ Yes, since		
Diarrhea	☐ No	☐ Yes	Frequency	
			Bloody Yes ☐ No ☐	
Chronic inflammatory bowel disease	☐ No	☐ Yes, since		(Year)
changes with you or in the family				
Osteoporosis	☐ No	☐ Yes, since		(Year)
Shortness of breath when climbing stairs	☐ No	☐ Yes, since		(Year)
Stroke	☐ No	☐ Yes, since		(Year)
Tuberculosis in you / in the family	☐ No	☐ Yes, since		(Year)
Rheumatic diseases				
in the family	☐ No	☐ Yes, since		(Year)

46. Which examinations have already been carried out due to illness?

Arthroscopy / Jointoscopy	No ☐	Yes ☐	Findings attached ☐	Year of investigation
Allergy test	No ☐	Yes ☐	Findings attached ☐	Year of investigation
Biopsy / tissue removal	No ☐	Yes ☐	Findings attached ☐	Year of investigation
Removal from the following organs				
Blood tests	No ☐	Yes ☐	Findings attached ☐	Year of investigation
Other blood tests (e.g. liver + kidney values etc.)	No ☐	Yes ☐	Findings attached ☐	Year of investigation
Bronchoscopy / lungoscopy	No ☐	Yes ☐	Findings attached ☐	Year of investigation

Computed tomography-CT / PET

No ☐ Yes ☐ Findings attached ☐ Year of investigation

CT / PET of the following organs:

Electroencephalography (EEG) - measurement of electrical activity in the brain

No ☐ Yes ☐ Findings attached ☐ Year of investigation

Simple electrocardiogram (ECG)

No ☐ Yes ☐ Findings attached ☐ Year of investigation

Long-term ECG

No ☐ Yes ☐ Findings attached ☐ Year of investigation

Exercise ECG

No ☐ Yes ☐ Findings attached ☐ Year of investigation

Electromyography (EMG) - measurement of muscle activity

No ☐ Yes ☐ Findings attached ☐ Year of investigation

Electroneurography (ENG) - measurement of nerve conduction velocity

No ☐ Yes ☐ Findings attached ☐ Year of investigation

Developmental diagnostics

No ☐ Yes ☐ Findings attached ☐ Year of investigation

Gastroscopy

No ☐ Yes ☐ Findings attached ☐ Year of investigation

Genetic examination

No ☐ Yes ☐ Findings attached ☐ Year of investigation

Investigation of the following genes:

Hormone test

No ☐ Yes ☐ Findings attached ☐ Year of investigation

Hearing test

No ☐ Yes ☐ Findings attached ☐ Year of investigation

Colonoscopy

No ☐ Yes ☐ Findings attached ☐ Year of investigation

Magnetic resonance imaging (MRI)

No ☐ Yes ☐ Findings attached ☐ Year of investigation

MRI of the following organs:

Pulmonary function test

No ☐ Yes ☐ Findings attached ☐ Year of investigation

Cerebrospinal fluid withdrawal (= withdrawal of nerve fluid from the spinal canal)

No ☐ Yes ☐ Findings attached ☐ Year of investigation

Ophthalmoscopy

No ☐ Yes ☐ Findings attached ☐ Year of investigation

X-ray examination

No ☐ Yes ☐ Findings attached ☐ Year of investigation

X-ray of the following organs:

Scintigraphy (= imaging representation of organ function)

No ☐ Yes ☐ Findings attached ☐ Year of investigation

Scintigraphy of the following organs:

Sonography / ultrasound

No ☐ Yes ☐ Findings attached ☐ Year of investigation

Sono / ultrasound of the following organs:

Tonometry / intraocular pressure measurement

No ☐ Yes ☐ Findings attached ☐ Year of investigation

Other investigations NOT mentioned

No ☐ Yes ☐ Findings attached ☐ Year of investigation

Following investigation

Medication

47. Which medications are currently being taken (including dietary supplements)?
A separate plan can be attached here (preferably created on the PC).

Name	Dosis (mg)	Dosing schedule				Duration (in Months)
		In the morning	Noon	In the evening	At night	

48. By sending you this form, you consent to us reviewing and archiving **your documents**.

Agree ☐ I do not agree ☐

49. Are you interested in participating in the study in the future?

Yes ☐ Further information is ☐
No ☐ desired

50. May we include you in an anonymous patient registry?

Yes ☐ Further information is ☐
No ☐ desired

X. Declaration of consent / release from the obligation to maintain confidentiality

Please tick! (Please delete as appropriate.)

☐ I hereby agree that doctor's letters / findings / other original files from examinations (e.g. MRI images) relating to my person are saved and, if necessary, given and forwarded to further care centers / doctors.

☐ I completed and understood the questionnaire myself.

Place and date _____ Signature _____