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 ☐ w ☐ 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 ☐ search for expert ☐
disease ☐ second opinion ☐
Other reason ☐ in fact ____________________

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

☐ No ☐ Yes, suspicion of: ____________________

19. Wurde bei Ihnen bereits eine seltene Erkrankung diagnostiziert?

☐ 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: ______________

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

____

Please mark all of your affected organ systems:

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

____

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 ______________

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

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 ☐ Specialist ☐ Other:
family doctor ☐ Family ☐ ______________________

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

____

____

34. Has the diagnosis changed in the meantime?

No
Yes

Earlier diagnosis was: ______________________

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

No
Yes, that is

Diagnosis 1 ______________________
Diagnosis 2 ______________________
Diagnosis 3 ______________________
Diagnosis 4 ______________________

36. Do you have pets? Yes Yes, that is ______________ No

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

____

Diagnostic route

38. 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 (Surname) ______________ visited on (month / year): ______________

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

No ☐ Yes

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

40. 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): ______________

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

Allergist	☐	Homoeopath	☐	Psychiatrist
General practitioners		Human geneticist	☐	Psychologist
Ophthalmologist		Immunologe	☐	Psychoso-matiker
Chiropractor		Internist		Radiologist/ Nuclear medic
Surgeon		Cardiologist		Rheuma tologist
Diabetologist		Pediatrician		Pain therapist
Endocrinologist		Pulmonologist		Environmental medic
Gynecologist		Neurochirurg		Urologe
Gastroenterologist		Neurologist	☐	Dentist
Vascular doctor	☐	Kidney doctor		
Haematologist	☐	Oncologist		
Dermatologist	☐	Orthopedist	☐	
ENT doctor		Pathologist		

Others ____________________

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

No ☐

Yes ☐

Internet ☐

Self-help group / patient organization ☐

Other: ☐ ____________________

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

	No	Yes		
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 Disturbed pain	☐ No	☐ Rare	☐ never	
Back pain	☐ No	☐ Yes	☐ at night, too	
Back pain with Radiance in one leg	☐ No	☐ left	☐ right	
Back pain with Radiance in one arm	☐ No	☐ left	☐ right	
Painful white, connecting of the hands turning blue in the cold	☐ No	☐ left	☐ right	
Inflammation / redness of the eyes	☐ No	☐ Yes, since		(Year)
Dryness of the eyes / mucous skins (also mouth, genital area	☐ No	☐ Yes, since		(Year)
Other changes to the skin and mucous membranes (also mouth, genital area)	☐ No	☐ Yes, since		(Year)
Painful urination	☐ No	☐ Yes, since		
Diarrhea	☐ No	☐ Yes	Frequency Bloody Yes ☐ No ☐	
Chronic inflammatory bowel disease changes with you or in the family	No	Yes, since		(Year)
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)

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

	No	Yes	Findings attached	Year of investigation
Arthroscopy / Jointoscopy	☐	☐	☐	
Allergy test	☐	☐	☐	
Biopsy / tissue removal	☐	☐	☐	

Removal from the following organs

	No	Yes	Findings attached	Year of investigation
Blood tests	☐	☐	☐	
Other blood tests (e.g. liver + kidney values etc.)	☐	☐	☐	
Bronchoscopy / lungoscopy	☐	☐	☐	

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 (EKG)

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

Electronurography (ENG) - measurement of nerve conduction velocity

No ☐ Yes ☐ Findings attached ☐ Year of investigation

Developmental diagnostics

No ☐ Yes ☐ Findings attached ☐ Year of investigation

Gastroscopy / 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 / 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 / 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

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

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

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

Agree ☐ I do not agree ☐

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

Yes ☐
No ☐
Further information is desired ☐

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

Yes ☐
No ☐
Further information is 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