Universitätsklinikum des Saarlandes

Zentrum für
Seltene Erkrankungen

Questionnaire for patients with an unclear diagnosis

A.

1. General Information regarding the Patient:

Name, First Name	
Date of Birth	
Gender	
Height	
Weight	
Marital Status, Children	
Nationality	
Profession, Occupation	
Address	
Telephone, Email	
Insurance Status	

2. Information regarding the declaring Person:

If you are not the patient, please state your relationship: **Family:** **Physician:** **Other:**
If you are not the patient, please state your contact information: **Addresse** **Telephone:** **Email:**

B.

3. Reason for the contact:

☐ Diagnosis

☐ Search for an Expert

☐ Second Opinion

- [ ] Information
- [ ] Other Reason:

4. **Were you diagnosed with a rare disease?**

- [ ] no
- [ ] yes, namely: ______________________________

5. **Was a concrete suspicion of a rare disease diagnosed?**

- [ ] no
- [ ] yes, suspicion on: ______________________________

6. **How did you become aware of the Center for Rare Diseases?**

- [ ] Physician
- [ ] Internet
- [ ] Support Group/Patient Organization
- [ ] Family/Friends
- [ ] Press/Radio/TV
- [ ] ZSE UKS homepage
- [ ] Other: ______________________________

7. **Have you already been to another Center for Rare Diseases?**

- [ ] no
- [ ] yes, namely: ______________________________

8. **Have you already been to the Universitätsklinikum des Saarlandes due to the current complaints/ rare disease or the suspicion of a rare disease?**

- [ ] no
- [ ] yes, namely (Year/Department/Diagnosis) ______________________________

____

C.

9. **What are your main complaints? Please state them and their severity of a scale**

of 1 (low) to 5 (very severe) below.

	Main complaint	Year of occurrence	Severity (1-5)
1.			
2.			
3.			
4.			
5.			
6.			
7.			
8.			

10. Which complaints or anomalies and when were they considered the start of the disease? Are there situations (Activities, time of day or the like), which improve or worsen the complaints?

11. Which treatments have already been performed and what was the respective effect to the complaints?

12. Please check all of your affected organ systems:

	Eyes		Skin		Stomach
	Pancreas		Heart		Spleen
	Hematopoiesis		Hormone system		Muscles
	Bronchi		Immune system		Nose
	Intestines		Larynx		Adrenal glands
	Gall bladder		Bones		Nerves

	Brain		Circulation		Kidneys
	Joints		Liver		Ears
	Genitalia		Lung		Thyroid
	Neck		Lymph nodes		Teeth

13. Which physicians have already been consulted regarding clarification of the current complaints?

	Allergologist		Hemostaseologist		Nuclear Physician
	General Practitioner		Human geneticist		Oncologist
	Ophthalmologist		Immunologist		Orthopedist
	Surgeon		Internist		Psychiatrist
	Diabetologist		Cardiologist		Psychosomatic Spec.
	Endokrinologist		Cardiosurgeon		Radiologist
	Gynecologist		Orthodontist		Rheumatologist
	Phlebologist/Angiologist		Pediatrician		Pain therapist
	Gastroenterologist		Pulmonary Specialist		Other:
	Ear-Nose-Throat Doctor		Neurosurgeon		
	Dermatologist		Neurologist		
	Hematologist		Renal Specialist		

14. Have/had any of your family members similar complaints?

☐ no

☐ yes, namely ______________________________

____

15. Are there any genetic diseases in your family?

☐ no

☐ yes, namely ______________________________

____

D.

16. Are there any other (chronic) diseases that are not in direct connection with the above-mentioned complaints?

	Disease	**Since?**
1.		
2.		
3.		
4.		
5.		
6.		
7.		
8.		

17. Please state any medications (including dietary supplements, Homeopathic medications, and herbs) that you are currently taking.

	Medication	Dosage	Since?
1.			
2.			
3.			
4.			
5.			
6.			
7.			
8.			

18. Please state all foreign travel, especially those prior to the start of the disease.

	Country/Region	Timeframe
1.		
2.		
3.		
4.		
5.		
6.		
7.		
8.		

19. Do you smoke?

☐ yes, number of cigarettes/day, for how many years:

☐ I quit: ______________________________

☐ I never smoked

20. Do you drink alkohol?

☐ yes

☐ not anymore, since: ______________________

☐ no

21. Do you have special dietary habits (e.g. vegetarian, vegan)

☐ no

☐ yes

22. Do you have pets?

☐ no

☐ yes, namely:

E.

23. Mental complaints (Psyche) accompany or influence the physical complaints (Soma). With this questionnaire (PHQ-D German translation of the „Patient Health Questionnaire (PHQ)“ by B. Löwe, S. Zipfel and W. Herzog, Medizinische Universitätsklinik Heidelberg. (English Original: Spitzer, Kroenke & Williams, 1999**) we want to ensure, that we treat you holistically. Your answers will help us understand your complaints better.**

1. How severely have the following complaints affected your day-to-day life in the last 4 weeks?

	Not at all	Somewhat	Severely
a. Abdominal pain			
b. Back pain			
c. Pain in the arms, legs, or joints (Knee, hips etc.)			
d. Menstruation pain or other problems with menstruation			
e. Pain or problems during intercourse			
f. Headaches			
g. Pain in the chest area			
h. Vertigo			
i. Fainting spells			
j. Palpitations or Tachycardia			
k. Shortness of breath			
l. Constipation, irritable bowels or diarrhea			
m. Nausea, flatulence or indigestion			

2. How severely have the following complaints affected your day-to-day life in the last 2 weeks?

	Not at all	Occasionally	On more than half the days	Almost every day
a. Little interest or joy in your activities				
b. Dejection, wistfulness or hopelessness				
c. Difficulty falling asleep or sleeping through the night, or increased sleep				
d. Fatigue or the feeling of having no energy				
e. Decreased appetite or the excessive need to eat				
f. Bad opinion of yourself; the feeling of being a loser or to have disappointed the family				
g. Difficulty to concentrate on something, e.g. while reading or watching TV				

h. Were your movements or speech so much slower that others would've noticed? Or the opposite, were you „antsy“ or restless and because of this had a bigger need to keep moving than normal?				
i. Thoughts that you would rather be dead or want to harm yourself				

3. Questions regarding „Anxiety“

	NO	YES
a. Have you had a panic attack in the last 4 weeks (sudden feeling of fear or panic)?		
b. Has this happened before?		
c. Do some of these attacks occur completely unexpected – i.e. in situations, in which you did not expect to feel anxious or restless?		
d. Do you perceive these events as severely restraining, and/or are you anxious of renewed events?		

4. Please think back to your last bad anxiety attack (if you did not have an anxiety attack in the last 4 weeks, you do not need to answer the following questions).

	NO	YES
a. Did you have problems breathing?		
b. Did you experience tachycardia, palpitations or an irregular heartbeat?		
c. Did you experience pain or a feeling of pressure in your chest?		
d. Did you sweat?		
e. Did you feel like you were suffocating?		
f. Did you experience hot flashes or shivers?		
g. Were you nauseous, did you have stomach complaints, or the feeling of getting diarrhea?		
h. Did you experience vertigo, the feeling of insecurity, wooziness, or close to fainting?		
i. Did you experience tingling or a feeling of numbness in parts of your body?		
j. Did you shake or quiver?		
k. Were you afraid you could die?		

5. How often did the following complaints impair you day-to-day in the last 4 weeks?

	Not at all	Occasionally	More than half of the days

a. Nervousness, anxiety, tension or excessive worrying If „Not at all“, you do not need to answer questions b-g.			
b. Feelings of unrest, so that sitting still is difficult			
c. Mild fatiguability			
d. Muscle tension, muscle pain			
e. Difficulty falling asleep or sleeping through the night			
f. Difficulty concentrating on something, e.g. while reading or watching TV			
g. Mild irritability, hypersensitivity			

6. Questions regarding „eating“

	NO	YES
a. Do you often feel like you cannot control what and how much you eat?		
b. Do you often eat – in a timeframe of 2 hours – amounts that other people would call unusually large? If „NO“ for a or b skip to question 9.		
c. In the last 3 months, has this happened at least twice / week?		

7. In the last 3 months, have you used one or multiple of the following measures to avoid gaining weight?

	NO	YES
a. Made yourself throw up?		
b. Taken more than double the recommended dose of a laxative?		
c. Did you fast, i.e. eat nothing for at least 24h?		
d. Exercised for more than one hour with the only target not to gain wait when you ate as described above (6a or 6b)?		

8. If you checked „YES“ with one or multiple of these measures to avoid weight gain, has one of them happened at least twice / week?

☐ no

☐ yes

9. Do you sometimes drink alcohol (including wine or beer)? If „NO“, skip to question 11

☐ no

☐ yes

10. Has one of the following situations occurred more than once in the last 6 months?

	NO	YES
a. You drank alcohol even though a doctor recommended to quit due to your health?		

b. You drank alcohol, were drunk, or had a hangover during work, in school, or while taking care of children or taking care of other responsibilities?		
c. You skipped or were late to work, school or other responsibilities because you had been drinking or had a hangover?		
d. You had difficulty getting along with others because you had been drinking?		
e. You drove a car after you had too much alcohol?		

11. If one or multiple of the, in this questionnaire, described problems are present with you, please state how these problems have impaired your ability to do your job, regulate your household, or how you get along with other people:

- ☐ Not at all
- ☐ Somewhat
- ☐ Relatively impaired
- ☐ Severely impaired

12. How much have the following complaints made you feel aggrieved in the last 4 weeks?

	Not at all	Somewhat	Severely
a. Worries about your health			
b. Worries about your weight and looks			
c. Little to no sexual desire or joy during intercourse			
d. Difficulty with the spouse, partner, girlfriend/boyfriend			
e. Stress due to caring for children, parents, or other family members			
f. Stress at work or in school			
g. Financial problems or worries			
h. Having no-one to discuss problems with			
i. Something bad that happened recently			
j. Thoughts of horrible events from the past or dreams about it – e.g. the destruction of the home, a severe accident, physical or sexual abuse			

F

Declaration of consent

With this I agree that my medical reports/findings/ other original files from examinations (e.g. CT images) regarding my person may be saved.

With this I agree that, in the scope of interdisciplinary case conferences (also with participating representatives from outside of the Universitätsklinikum des Saarlandes), my case and my documents may be forwarded for the discussion of my illness.

Are you interested in the participation of future studies?

- ☐ yes
- ☐ no
- ☐ Requesting further information

May we add you to an anonymous patient register?

- ☐ yes
- ☐ no
- ☐ Requesting further information

I have personally filled out and understood the questionnaire.

- ☐ yes

This consent can be retracted at any time.

________________________	__________________________________
City, Date	Signature Patient

________________________	__________________________________
City, Date	Signature legal guardian (e.g. parents)