

## National paediatric rheumatology database 2026

Hier bitte  
„Einrichtungsetikett“  
aufkleben!

**ID-Nr.:**  Bitte ID-Nummer eintragen unter welcher Pat. geführt wird

# **Questionnaire for parents with children suffering from rheumatic diseases (for patients < 12 years)**

Hier bitte Etikett für neue / erstmalig  
dok. Patient:innen aufkleben!

As you have already read in the information sheet, we would like to ask you to fill in the following questionnaire. **Please try to answer every question.**

1. When did your child's rheumatic complaints begin?   |  |  | month   |  |  |  | year
2. When did you first present your child to a pediatric rheumatologist?   |  | month   |  |  |  | year
3. How long did it take from the referral until your child's first appointment with a pediatric / adolescent rheumatologist?  
Number of days   |   and weeks   |  |    I don't know
4. Has your child been absent from kindergarten/school due to his/her rheumatic disease during the past 12 months?  
 no  yes, namely:   |  |  |  |   days
5. Has your child been hospitalized due to his/her rheumatic disease in the past 12 months?  
 no  yes, namely:   |  |   weeks and   |   days
6. Which of the following treatments has your child received in the last 12 months?  
Please indicate only those treatments that have been prescribed by a doctor and that your child received on an outpatient basis, i.e. not during a hospital stay or a rehabilitation or cure measure.  
 physiotherapy (individually or in a group)  aquatic training (individually or in a group)  
 occupational therapy (e.g. joint protection consultation, aids)  my child has not received any such treatment
7. Have you or your child participated in an education program to manage your child's rheumatic disease in the last 12 months? Examples: Training weekend of the Rheuma-Liga, Rheumacamp, during a hospital stay  
 no  yes
8. Has your child taken part in a rehabilitation or medical cure measure due to his/her rheumatic disease in the past 12 months?  
 no  yes
9. Does your child use orthopedic aids?  
 no  yes, namely:  splints and bandages (e.g. for knee, wrist)  
 orthopedic shoes  cervical cuff  
 insoles/shoe lifts

14. In this section we are interested in learning how your child's disease affects his/her ability to function in daily life. In the following questions, please check the response which best describes your child's usual activities (averaged over an entire day) over the past week.

	without any difficulty	with some difficulty	with much difficulty	unable to do	not applicable
<b>1. Dressing and Grooming</b>					
Is your child able to:					
• Dress, including tying shoelaces and doing buttons?	<input type="checkbox"/>				
• Shampoo his/her hair?	<input type="checkbox"/>				
• Remove socks?	<input type="checkbox"/>				
• Cut fingernails?	<input type="checkbox"/>				
<b>2. Arising</b>					
Is your child able to:					
• Stand up from a low chair or the floor?	<input type="checkbox"/>				
• Get in and out of bed or stand in crib?	<input type="checkbox"/>				
<b>3. Eating</b>					
Is your child able to:					
• Cut his/her own meat?	<input type="checkbox"/>				
• Lift a cup or a glass to mouth?	<input type="checkbox"/>				
• Open a new cereal box?	<input type="checkbox"/>				
<b>4. Walking</b>					
Is your child able to:					
• Walk outdoors on a flat ground?	<input type="checkbox"/>				
• Climb up five steps?	<input type="checkbox"/>				
<b>5. Hygiene</b>					
Is your child able to:					
• Wash and dry entire body?	<input type="checkbox"/>				
• Take a tub bath (get in and out of the tub)?	<input type="checkbox"/>				
• Get on and off the toilet or the potty chair?	<input type="checkbox"/>				
• Brush teeth?	<input type="checkbox"/>				
• Comb/Brush hair?	<input type="checkbox"/>				
<b>6. Reach</b>					
Is your child able to:					
• Reach and get down a heavy object such as a large game or books from just above his/her head?	<input type="checkbox"/>				
• Bend down to pick up a piece of clothing or a piece of paper from the floor?	<input type="checkbox"/>				
• Pull on a sweater over his/her head?	<input type="checkbox"/>				
• Turn neck to look over shoulder?	<input type="checkbox"/>				
<b>7. Grip</b>					
Is your child able to:					
• Write or scribble with a pen or pencil?	<input type="checkbox"/>				
• Open car doors?	<input type="checkbox"/>				
• Open jars which have been previously opened?	<input type="checkbox"/>				
• Turn faucets on and off?	<input type="checkbox"/>				
• Push open a door when he/she has to turn knob?	<input type="checkbox"/>				
<b>8. Errands, chores and play</b>					
Is your child able to:					
• Run errands and shop?	<input type="checkbox"/>				
• Get in and out of car or toy car or school bus?	<input type="checkbox"/>				
• Ride bike or tricycle?	<input type="checkbox"/>				
• Do household chores (e.g. wash dishes, take out trash, vacuuming, yardwork, make bed, clean room)?	<input type="checkbox"/>				
• Run and play?	<input type="checkbox"/>				

**Please check any aids or devices that your child usually uses for the mentioned activities:**

My child does not need any aids or devices

My child usually uses the following aids or devices:

1. Dressing and grooming:	<input type="checkbox"/> Devices used for dressing (button hook, zipper pull, long-handled shoe horn, etc.)
2. Arising:	<input type="checkbox"/> Special or built up chair
3. Eating:	<input type="checkbox"/> Devices used for eating
4. Walking:	<input type="checkbox"/> Cane <input type="checkbox"/> Walker <input type="checkbox"/> Crutches <input type="checkbox"/> Wheelchair
5. Hygiene:	<input type="checkbox"/> Raised toilet seat <input type="checkbox"/> Bathtub seat <input type="checkbox"/> Bathtub bar
6. Reach:	<input type="checkbox"/> Long-handled appliances for reach
7. Grip:	<input type="checkbox"/> Long-handled appliances in bathroom <input type="checkbox"/> Built up pencil or special utensils <input type="checkbox"/> Jar openers (for jars previously opened)
8. Other:	<input type="checkbox"/> Specify: _____

Please check any categories for which your child usually needs help from another person because of his/her disease:

My child does not need any help

My child usually needs help for:

<input type="checkbox"/> Dressing	<input type="checkbox"/> Walking	<input type="checkbox"/> Gripping
<input type="checkbox"/> Arising	<input type="checkbox"/> Hygiene	<input type="checkbox"/> Errands and chores
<input type="checkbox"/> Eating and drinking	<input type="checkbox"/> Reach	

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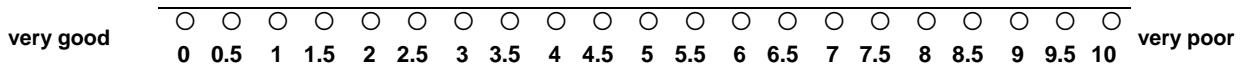
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*The following questions are about your child's physical activities and sleeping patterns.*

15. On how many days during a normal week is your child physically active for at least 60 minutes?

on 7 days       on 6 days       on 5 days       on 4 days  
 on 3 days       on 2 days       on one day       none

**16. How would you rate your child's sleep for the past 2 weeks overall?**

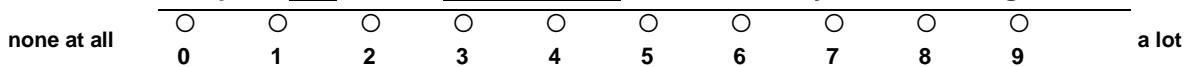


**17. How is your child coping with his or her rheumatic disease at the moment?**



*In the following three questions we ask for your evaluation of the way you were treated. Please keep in mind the last appointment at the rheumatology outpatient clinic.*

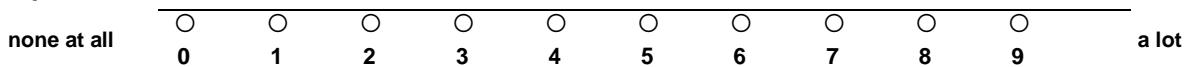
**18. How much help did you receive to understand the reason for your child being here?**



**19. How much attention was paid to what matters most to you?**



20. How much consideration was given to what is most important to you when planning the next steps?



Please also answer the following questions about your satisfaction with your child's care.

**21. Were you sufficiently involved in decisions about your child's treatment?**

yes, (almost) always     often     sometimes     rarely     not at all  
 not applicable, no treatment was carried out

**22. How satisfied are you with your child's drug therapy?**

not satisfied     partially satisfied     satisfied     very satisfied     extremely satisfied  
 not applicable, my child does/did not receive any drug therapy

**23. Were you informed about your child's rheumatic disease and therapy as part of your child's care or were you told where to find further information?**

yes, sufficiently     yes, but not sufficiently     no

**24. Information concerning your child's illness and its diagnosis.**

Were you satisfied with...	not satisfied	partially satisfied	satisfied	very satisfied	extremely satisfied
...the information about different treatment options?	<input type="radio"/>				
... with the information given about your child's illness?	<input type="radio"/>				
... with the time it took to diagnose the illness?	<input type="radio"/>				

**25. The way your child was treated by the specialist. Please keep in mind your last visit at the clinic/outpatient practice**

Were you satisfied with ...	not satisfied	partially satisfied	satisfied	very satisfied	extremely satisfied
... with the efforts made to make your child feel comfortable?	<input type="radio"/>				
... with the doctor's attention to your child?	<input type="radio"/>				

**26. Satisfaction with the specialist. Please keep in mind your last visit at the clinic/outpatient practice.**

Were you satisfied with ...	not satisfied	partially satisfied	satisfied	very satisfied	extremely satisfied
... with the doctors' ability to explain things clearly?	<input type="radio"/>				
... with the time the doctors had for you and your child?	<input type="radio"/>				

**27. Overall satisfaction with your child's health care. Please think about the last 12 months.**

Were you satisfied with ...	not satisfied	partially satisfied	satisfied	very satisfied	extremely satisfied
... the health care of your child in general?	<input type="radio"/>				

Finally, we have a few questions about your child and your family.

**28. Which school does your child attend?**

no school     elementary school     lower secondary school (Hauptschule)     secondary school (Realschule)  
 comprehensive school (Gesamtschule)     grammar school (Gymnasium)     other school: \_\_\_\_\_

**29. In case of going to school, did your child participate in PE (physical education) in the last 4 weeks?**

almost always     sometimes not     often not  
 my child is partly exempt from school sports     my child is fully exempt from school sports

**30. How is your child looked after during the day after school?**

- at home
- daycare mother
- Kindergarten
- day nursery
- after-school care / all-day school
- other care
- my child does not need any care after school

**31. Have you had to take time off work in the last 6 months because of your child's rheumatic illness?**

## Own information

## Information for another person with custody rights

not applicable, not employed       not applicable, not employed  
 no       yes, in fact: |\_\_| days       no       yes, in fact: |\_\_| days

**32. Are there other children living in your household?**

no       yes, namely       children aged              years  
*Please fill in the number of children and their age!*

### **33. With whom does the child live in a household?**

mother       father       stepmother/-father       grandparents  
 siblings       other persons       child does not live within its family

### 34. Does your child have a disabled person's pass?

no       yes      ⇒ degree of disability        code

Finally, for reasons of comparability, we ask you to answer some questions taken from the Robert Koch Institute's KiGGS study on the health of children and adolescents in Germany. By father and mother, we mean the person that lives in a household with the child. The term mother or father also refers to the person that takes the place of the biologic parents, e.g., the father's partner, stepfather, or others.

**35. What is your highest general school-leaving qualification?**

	mother	father
not yet graduated (still a student)	<input type="radio"/>	<input type="radio"/>
graduation after a maximum of 7 years of school attendance	<input type="radio"/>	<input type="radio"/>
lower secondary school education	<input type="radio"/>	<input type="radio"/>
middle secondary school education	<input type="radio"/>	<input type="radio"/>
higher education entrance qualification	<input type="radio"/>	<input type="radio"/>
other school-leaving qualification	<input type="radio"/>	<input type="radio"/>

**36. The following questions are about your professional training and your professional position.**

### **Highest professional qualification**

**Occupational status** (If you are no longer in employment, please state your last occupation)

		<i>employment, please state your last occupation)</i>				
		mother	father	mother	father	
still in vocational training		<input type="radio"/>	<input type="radio"/>	employee	<input type="radio"/>	<input type="radio"/>
no vocational qualification		<input type="radio"/>	<input type="radio"/>	worker	<input type="radio"/>	<input type="radio"/>
apprenticeship (vocational-operational training)		<input type="radio"/>	<input type="radio"/>	civil servant	<input type="radio"/>	<input type="radio"/>
technical college (vocational-educational training)		<input type="radio"/>	<input type="radio"/>	self-employed <u>with</u> employees	<input type="radio"/>	<input type="radio"/>
professional school (e.g. master school, technical school vocational academy)		<input type="radio"/>	<input type="radio"/>	self-employed <u>without</u> employees	<input type="radio"/>	<input type="radio"/>
polytechnic college		<input type="radio"/>	<input type="radio"/>	assisting family member	<input type="radio"/>	<input type="radio"/>
university		<input type="radio"/>	<input type="radio"/>	apprentice	<input type="radio"/>	<input type="radio"/>
other professional qualification		<input type="radio"/>	<input type="radio"/>	never been gainfully employed	<input type="radio"/>	<input type="radio"/>
				other	<input type="radio"/>	<input type="radio"/>

### 37. Where does your child live? Please enter your postcode

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Today's date: 1 1 1 2 6

Many thanks for your help!