SNAKE

[SCHLAFFRAGEBOGEN FÜR KINDER MIT NEUROLOGISCHEN UND ANDEREN KOMPLEXEN ERKRANKUNGEN]

SLEEP QUESTIONNAIRE FOR CHILDREN WITH SEVERE PSYCHOMOTOR IMPAIRMENT

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Sleep Questionnaire for Children with Severe Psychomotor Impairment
Version 1.0

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Paediatric Palliative Care Centre
Children`s and Adolescent`s Hospital, Datteln
Witten/Herdecke University

Vestische Kinder- und Jugendklinik Datteln
Universität Witten/Herdecke

Dear Parents,

This questionnaire should help us to get an extensive overview of your child's sleep condition in order to initiate comprehensive treatment. All information being gathered from this and further questionnaires as well as information gained in the talks will be treated as strictly confidential.

Please answer all questions, even those that appear unimportant to you. Sleep problems are very complex, so that even seemingly unimportant details are of importance to us. If you do not understand a question, please highlight this question with a question mark.

Your data and your child's data are subject to **medical confidentiality**.

It is our goal to further improve the detection, diagnosis and treatment of children with sleep problems. In order to achieve this goal, we rely on information on you and your child. Information will be stored and further analyzed anonymously, i.e. there is no link between information and the actual person.

We kindly ask you for your agreement to store the data on you and your child.

This agreement can be taken back at any time without giving reasons. In case you do not want to agree to the use of your data, or if you decide to take back the agreement at any given point of time, there will of course be **no disadvantage** to your child's treatment.

Your Palliative Care Team

AGREEMENT

First and last name of your child

I AGREE TO STORING AND ANONYMOUSLY USING MY AND MY CHILD'S DATA AS ASSESSED IN THE QUESTIONNAIRES.

- ○ Yes
- ○ No

Place / Time

Signature of both parents**

** In case of special family situations (e.g. parent's divorce, single mother/father), we seek information on the attachment figure living with your child for at least one year.

GENERAL INFORMATION ON THE CHILD AND THE FAMILY

QUESTIONNAIRE IS FILLED OUT BY:

◯ mother ◯ father ◯ other: .....

GENERAL INFORMATION ON YOUR CHILD:

Sex: ◯ female ◯ male country of birth: .....

Age: ..... years height: ..... feet weight: ..... pounds

What diagnosis (diagnoses) was (were) made for your child?

.....

.....

.....

What medication does your child take?

name: ..... dosage: .....

name: ..... dosage: .....

name: ..... dosage: .....

name: ..... dosage: .....

name: ..... dosage: .....

Caregiver's marital status?

◯ parents live together ◯ parents are divorced since: .....

◯ parent widowed since ..... ◯ parents never lived together .....

With whom does your child live predominantly?

◯ biological parents ◯ biological mother ◯ biological father

◯ biological mother and partner ◯ biological father and partner

◯ grandparents or other relatives ◯ adoptive parents ◯ foster parents

◯ children's home ◯ others (please specify) .....

How many children live in your household? ..... children

How many persons (including children) live in your household? ..... persons

PART I – SLEEPING HABITS

THE FOLLOWING QUESTIONS RELATE TO **YOUR CHILD'S** USUAL SLEEP HABITS DURING THE PAST **4 WEEKS.** PLEASE CONSIDER THIS TIME FRAME IN ALL QUESTIONS.

1. At what time did you usually put **your child** to bed at night?	about ..... o'clock
2. How long did it usually take for **your child** to fall asleep?	about ..... minutes
3. How many hours of sleep did your child actually get at night?	about ..... hours

4. Please choose the one answer, which describes your child the most accurate in the **past 4 weeks.**

	Never	Less than once a week	Once or twice a week	Three or more times a week
4a. How often did your child resist going to bed (at bedtime)?	○	○	○	○
4b. How often was **your child** afraid of falling asleep or of being alone?	○	○	○	○
4c. How often did **your child** need your help to fall asleep?	○	○	○	○
4d. How often did **your child** have restless sleep and rolling movements while it was falling asleep?	○	○	○	○
4e. How often did **your child** wake up during the night?	○	○	○	○
4f. How often did **your child** have trouble falling asleep again if awakened?	○	○	○	○
4g. How often did **your child** sleep in your bed at night?	○	○	○	○
4h. How often did **your child** sleep in a room with other people?	○	○	○	○
4i. How often did **your child** take medication to help him/her sleep (prescribed or „over the counter")? name: dosage:				

5. HOW LONG WOULD YOU SAY YOUR **CHILD** WAS AWAKE AT NIGHT ON AVERAGE?

about..... hours

6. HOW WOULD YOU RATE **YOUR CHILD'S** SLEEP QUALITIY OVERALL?

◯ very good ◯ good

◯ satisfactory ◯ poor

SPECIFY FOR THE FOLLOWING QUESTIONS HOW OFTEN THESE SITUATIONS OCCURED IN THE **PAST 4 WEEKS.**

7. HOW OFTEN ...

	Never	Less than once a week	Once or twice a week	Three or more times a week
7a. ... were the lights switched on in **your child's** bedroom?	◯	◯	◯	◯
7b. ... could noise (e.g. street noise) be heard in **your child's** bedroom?	◯	◯	◯	◯
7c. ... was the radio or TV running in **your child's** bedroom?	◯	◯	◯	◯
7d. ... was the door open in **your child's** bedroom?	◯	◯	◯	◯

8. HOW OFTEN DID **YOUR CHILD** HAVE A BAD SLEEP BECAUSE OF ...

	Never	Less than once a week	Once or twice a week	Three or more times a week
8a. ...pain?	◯	◯	◯	◯
8b. ... epileptic seizure?	◯	◯	◯	◯
8c. ... breathing difficulties?	◯	◯	◯	◯
8d. ... repositioning?	◯	◯	◯	◯
8e. ... medical care such as infusion, corset, respirator etc.?	◯	◯	◯	◯
8f. ... other reason(s)?	◯	◯	◯	◯

Please specify:

9. WHEN **YOUR CHILD** COULD NOT SLEEP AT NIGHT, WHAT DID HE / SHE DO?

	Never	Less than once a week	Once or twice a week	Three or more times a week
9a. ... lying restlessly in his/her bed.	○	○	○	○
9b. ... crying and screaming in his/her bed.	○	○	○	○
9c. ... doing other things.	○	○	○	○

Please specify:

10. HOW OFTEN DID **YOUR CHILD** DO ONE OF THE FOLLOWING THINGS WHILE HE / SHE WAS ASLEEP AT NIGHT?

	Never	Less than once a week	Once or twice a week	Three or more times a week
10a. ... snore?	○	○	○	○
10b. ... pause between breaths?	○	○	○	○
10c. ... tilt his/her head?	○	○	○	○
10d. ... grind teeth?	○	○	○	○
10e. ... sweat excessively?	○	○	○	○
10f. ...doing other things?	○	○	○	○

Please specify:

PART II – DAYTIME ACTIVITY

THE FOLLOWING QUESTIONS RELATE TO **YOUR CHILD'S BEHAVIOR WHILE WAKING UP AND DURING THE DAY.**
PLEASE CONSIDER AGAIN THE **PAST 4 WEEKS** FOR ALL QUESTIONS.

11. AT WHAT TIME DID **YOUR CHILD** USUALLY WAKE UP IN THE MORNING?

at about ..... o'clock

12. HOW OFTEN DID **YOUR CHILD** FALL ASLEEP DURING THE DAY?
PLEASE MARK THE BEST FITTING CATEGORY WITH A CROSS. PLEASE CONSIDER AGAIN THE **PAST 4 WEEKS** FOR ALL QUESTIONS.

◯ never ◯ less than once a week

◯ once or twice a week ◯ three or more times a week

13. WHEN YOUR CHILD HAD A BAD SLEEP AT NIGHT, HOW OFTEN DID HE / SHE SHOW ONE OF THE FOLLOWING CHARACTERISTICS DURING THE DAY?

	Never	Rarely	Sometimes	Often
13a. show physical exhaustion	◯	◯	◯	◯
13b. fall asleep unexpectedly	◯	◯	◯	◯
13c. become less balanced	◯	◯	◯	◯
13d. become restless	◯	◯	◯	◯
13e. show aggression	◯	◯	◯	◯
Please specify:				
13f. show other unusual behavior	◯	◯	◯	◯
Please specify:				

14. HOW MANY HOURS DID **YOUR CHILD** SLEEP DURING THE DAY IN TOTAL?

about .....hours

15. HOW MANY HOURS WAS **YOUR CHILD** RESTLESS DURING THE DAY IN TOTAL?

about ..... hours

WOULD YOU LIKE TO ADD SOMETHING THAT YOU CONSIDER IMPORTANT FOR YOUR CHILD'S SLEEPING BEHAVIOR OR ACTIVITY THAT WAS NOT ASSESSED WITH THIS QUESTIONNAIRE?

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THANK YOU VERY MUCH!

Paediatric Palliative Care Centre
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