

Supplement 1

Febrile seizures: Perceptions and knowledge of parents of affected and unaffected children

Questionnaire

For parents of children with at least one febrile seizure (FS-group)

1.) a) Did you realize your child had a febrile seizure?

- ☐ Yes
- ☐ No
- ☐ No statement

b) If no, what did you think happened? (open question)

2.) a) What was the dominating feeling when your child had a febrile seizure? (open question)

b) On a scale from 0 - 10 (0=least pronounced to 10=most pronounced), how strongly would you rate the feeling?

3.) Who told you, your child had a febrile seizure?

- ☐ A physician
- ☐ Someone else. Who? (open question)
- ☐ No one.
- ☐ I do not remember.

4.) Which issues were addressed in the first consultation about the diagnosis?

Acute measures to be taken in case of a febrile seizure

☐ Yes ☐ No ☐ No statement

Long-term consequences of febrile seizures

☐ Yes ☐ No ☐ No statement

Frequency of febrile seizures

☐ Yes ☐ No ☐ No statement

Measures to prevent febrile seizures

☐ Yes ☐ No ☐ No statement

Risk factors for febrile seizures

☐ Yes ☐ No ☐ No statement

Acute complications of febrile seizures

☐ Yes ☐ No ☐ No statement

5.) Changes after the febrile seizure

For parents of a child with at least one previous febrile seizure

- a) Were there any general changes in the handling of your child?
☐ Yes ☐ No ☐ No statement
- b) Do you take your child's temperature more often?
☐ Yes ☐ No ☐ No statement
- c) Do you give your child medicine to lower his/her fever earlier?
☐ Yes ☐ No ☐ No statement
- d) At what temperature do you start giving your child medicine to lower his/her fever? (open question)
- e) Do you see your pediatrician more often when your child has a fever?
☐ Yes ☐ No ☐ No statement

For parents of a child with a first febrile seizure:

- a) Will there be any general changes in the handling of your child?
☐ Yes ☐ No ☐ No statement
- b) Will you take your child's temperature more often?
☐ Yes ☐ No ☐ No statement
- c) Will you give your child medicine to lower his/her fever earlier?
☐ Yes ☐ No ☐ No statement
- d) At what temperature will you start giving your child medicine to lower his/her fever? (open question)
- e) Will you see your pediatrician more often when your child has a fever?
☐ Yes ☐ No ☐ No statement

For parents of children with at least one febrile seizure (FS-group) and parents of children who had not experienced a febrile seizure thus far (control group)

6.) For parents in the FS-group

Did you inform yourself on the topic of febrile seizures before your child was affected?

☐ Yes ☐ No

For parents in the control group

Have you informed yourself on the topic of febrile seizures yet?

☐ Yes ☐ No

7.) Which measures would you take in case of a febrile seizure?

Clear the surroundings

☐ Yes ☐ No ☐ No statement

Calm the child

☐ Yes ☐ No ☐ No statement

Administer an anti-seizure medication if available

☐ Yes ☐ No ☐ No statement

Call the emergency

☐ Yes ☐ No ☐ No statement

Document the length of the seizure

☐ Yes ☐ No ☐ No statement

Administer fever medication

☐ Yes ☐ No ☐ No statement

Put a solid object into the child's mouth

☐ Yes ☐ No ☐ No statement

8.) Do you know about possible negative consequences resulting from a febrile seizure?

Injuries

☐ Yes ☐ No ☐ No statement

Other febrile seizures

☐ Yes ☐ No ☐ No statement

Suffocation of the child

☐ Yes ☐ No ☐ No statement

Epilepsy

☐ Yes ☐ No ☐ No statement

Developmental disorder

☐ Yes ☐ No ☐ No statement

9.) a) Do you feel adequately prepared for a febrile seizure in your child?

- ☐ Definitely
- ☐ Rather yes
- ☐ Partly
- ☐ Rather no
- ☐ Definitely no
- ☐ I cannot judge my preparedness

b) What measures would you need to feel better prepared? (open question)

10.) Sociodemographic data parent

- a) Gender ☐ Male ☐ Female
- b) Age (years)
- c) Education
- ☐ No school graduation
 - ☐ "Hauptschule"/"Realschule" (schools that prepare mainly for vocational careers)
 - ☐ "Abitur" (i.e. the diploma for entry into higher education)
 - ☐ No statement
- d) Profession (open question)

11.) Sociodemographic data child

- a) Gender ☐ Male ☐ Female
- b) Age (months)
- c) Number of febrile seizures (n)
- d) Fever associated with the current hospitalization?
- ☐ Yes ☐ No