

1 **ARTICLE TITLE:**

2 Consensual statements on the information to deliver after a febrile seizure

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64 **ABSTRACT**

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66 Febrile seizures (FS) are usually self-limiting and cause no morbidity. Nevertheless they
67 represent very traumatic events for families. There is a need to identify key messages that
68 reassure carers and help to prevent inappropriate, anxiety-driven behaviours associated with
69 'fever phobia'. No recommendations have been proposed to date regarding the content of such
70 messages. Using a Delphi process, we have established a consensus regarding the information
71 to be shared with families following a FS.

72 Twenty physicians (child neurologists and pediatricians) from five European countries
73 participated in a three-step Delphi process between May 2018 and October 2019. In the first
74 step, each expert was asked to give 10 to 15 free statements about FS. In the second and third
75 steps, statements were scored and selected according to the expert ranking of importance.

76 A list of key messages for families has emerged from this process, which offer reassurance
77 about FS based on epidemiology, underlying mechanisms and the emergency management of
78 FS should they recur. Interestingly, there was a high-level of agreement between child
79 neurologists and general pediatricians.

80 *Conclusion:* We propose key messages to be communicated with families in the post-FS clinic
81 setting.

82

83 **KEYWORDS:**

84 Febrile seizure; fever phobia; Delphi; antipyretics; parental reassurance; consensus

85

86 **LIST OF ABBREVIATIONS:**

87 EEG: electroencephalogram

88 FS: febrile seizure

89 MRI: magnetic resonance imaging

90

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95 The authors declare no conflicts of interest. The authors confirm that they have read the
96 Journal's position on issues involved in ethical publication and affirm that this report is
97 consistent with those guidelines.

98 *Authors' contributions*

99 Pr. Auvin, Dr. Loussouarn and Dr. Dozières-Puyravel contributed to the study conception and
100 design. Material preparation, data collection and analysis were performed by Dr. Loussouarn
101 and Pr. Auvin. All authors generate the statements, scored the statements, wrote and edited
102 the tables. The first draft of the manuscript was written by Dr. Loussouarn and Pr. Auvin and
103 all authors commented and edited on previous versions of the manuscript. All authors read
104 and approved the final manuscript.

105 **MAIN TEXT**

106 **Introduction**

107 Febrile seizures (FS) are defined by the American Academy of Pediatrics as seizures
108 that occur during fever in the absence of intracranial infection¹. The prognosis is usually
109 excellent with no long-term consequences^{2,3,4}. However, FS are traumatic events for families⁵.
110 Parents frequently describe that at the moment their child experienced a FS, they feared their
111 child's imminent death⁶. Thus, there is a high risk of subsequent post-traumatic stress
112 disorder^{7,8}. Recurrence of FS prompts more than half of the parents to modify their parenting
113 behaviour⁹ by sleeping in the same room with their child or by measuring body temperature
114 multiple times per day⁶. Most of the parents exhibit sleep disturbance and a high level of
115 anxiety^{7,8}. In this context, the fear of fever may also lead to an overuse of antipyretics that might
116 be harmful¹⁰⁻¹³.

117 These modifications of parenting behaviors are probably motivated by fear^{6,14,15}, and
118 erroneous beliefs about FS, for example, that FS can cause brain damage and subsequent
119 intellectual and physical disability¹⁶. The influence of sociocultural factors on these flawed
120 beliefs is controversial^{16,17}. However, a systematic review described it as a common world
121 phenomenon¹⁶. Some studies report that these beliefs are shared and promulgated by poorly
122 informed healthcare professionals when their role is to share accurate information and reassure
123 parents^{5,12}.

124 Recommendations have been published regarding the neurodiagnostic evaluation of a
125 child with a simple FS¹⁸, diagnostic markers, management interventions, and outcome
126 measures of FS¹⁹. There are also website providing information on FS for parents and
127 caregivers (e.g. NINDS, Mayo clinic, etc.). However, no guidelines to date have addressed the
128 question of what information to share with parents following a FS in particular in the emergency
129 setting.

130 To this end we conducted a study involving child neurologists and pediatricians from
131 five European countries to achieve a consensus regarding the first key messages to be shared
132 with parents following a FS.

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135 **MATERIAL AND METHODS**

136 Two groups of 10 physicians (respectively, child neurologists and pediatricians working either
137 in general pediatric department, in the pediatric emergency room or both) participated in the
138 study from May 2018 to October 2019 with two pairs of specialists per country (France,
139 Germany, Italy, Spain, United Kingdom). The rationale of interviewing pediatricians from two
140 different subspecialties was motivated by the idea that these different points of view may be
141 complementary.

142 Our aims were shared with those experts in a short summary emphasizing that FS are
143 'very emotional events for parents', and could 'change the daily life of the whole family as well
144 as the parental attitudes' towards their child(ren).

145 A three-step Delphi process was undertaken separately for each group of experts. The
146 Delphi is a technique that aims at obtaining consensus on the opinions of 'experts'. By experts
147 is usually meant 'a panel of informed individuals'. Consensus is obtained through a multistage
148 process, replies to the first questionnaire being implementing the following, and so on^{20,21}. By
149 contrast to the usual method based on structured questionnaires, in this study we first collected
150 free statements. First, each expert provided 10 to 15 free statements representing key
151 messages to give to parents following a FS, without more precision. They were free to decide
152 whether to provide messages about simple FS, or to provide messages concerning both simple
153 and complex FS. Letting these two alternatives possible was a way to address the question of
154 whether this distinction is relevant to be communicated to parents, or whether it can be seen
155 too complex or stressful. These were collected without any selection. Secondly, participants
156 were asked to rate each statement obtained in the first step from 1 to 10, according to their
157 relevance (1 being less relevant). Participants were encouraged to use the whole scale and to
158 direct statements towards parents rather than healthcare professionals. Twenty statements
159 with the highest relevance scores were selected. In the third step, participants were invited to
160 select their 10 preferred statements from the 20 identified as most relevant and to rank them in
161 order of priority from 1 to 10 (1 being the highest priority).

162 The study did not require ethical approval. The data was then analyzed quantitatively
163 (i.e. the means of quotations for each proposition was calculated as well as standard deviations)
164 and qualitatively (i.e. the main thematics were extracted from the reading of all propositions and

165 comparisons were made between the information sharing statements that emerged from child
166 neurologists and those from pediatricians).

167

168 **RESULTS**

169 **Child neurologists Step 1** (Supplementary material table 1)

170 A total of 40 proposed information sharing statements were summarized for the first
171 round (Supplementary material table 1). Several statements were proposed by more than one
172 expert. According to a qualitative analysis, they can be gathered in five descriptive categories.

173 1) The first category focuses on an *epidemiological and definitional theme* where febrile
174 seizures, the population affected and frequency is described.

175 2) The second focuses on the *physiological mechanisms*. Several panel members wished to
176 emphasize the concept of an “individual-dependent temperature threshold” which triggers a FS.

177 3) The third category places FS in a realistic context emphasizing that they are not triggered by
178 every infection and have an excellent prognosis.

179 4) The fourth category focuses on the emergency care plan for parents to implement in the
180 event that FS recur.

181 5) The fifth and final category emphasizes that the diagnosis of FS is a clinical one in order to
182 prevent unnecessary investigations.

183

184 **Child neurologists Step 2** (Supplementary material Table 1)

185 Participants were then asked to score the 40 statements from 1 to 10 according to their
186 respective importance (1 meaning ‘less important’). Statements showed mean values of 3.2 to
187 9.5, and standard deviations from 0.8 to 3.8 indicating that participants had scored using the
188 whole scale. The five categories identified in step 1 were found again in the 20 highest scoring
189 statements in step 2 as follows:

190 - *Category 1*: “FS are common. For every 100 children, between 3 and 5 will experience
191 one or more FS.”

192 - *Category 2/3*: “In most cases, FS cease spontaneously within 2-3 minutes, and do not
193 require any treatment.”

194 - *Category 4*: “In the event of a FS, keep calm, make the environment safe to avoid harm
195 to the child, if possible place the child in the recovery position, do not put anything into
196 mouth or between teeth, note the duration and physical features of the seizure.”

197 - *Category 5*: “The diagnosis of FS is based on history and physical examination.
198 Laboratory tests, electroencephalogram and neuroimaging are not routinely
199 recommended.”

200 Statements rated at the lower end were those providing details about biological
201 mechanisms or about epidemiology. Some statements mentioned risk of recurrence (e.g. ‘after
202 24 hours of fever, the risk of appearance of FS is very low’), or the genetically determined
203 susceptibility to FS (e.g. ‘FS affect genetically predisposed individuals: the seizures are not
204 precipitated by fever’). The statements receiving the lowest scores were statements about the
205 risk of epilepsy in the future.

206 In summary, it is of value to examine the lowest scoring statements in addition to the
207 highest scoring ones as the lower scoring ones may reflect information that physicians would
208 freely share with parents but which may generate anxiety, confusion and generate the risk of
209 fever phobia.

210

211 **Child neurologists Step 3** (Supplementary material Table 2)

212 Experts then ranked the 20 highest scoring statements from step 2 in order of priority
213 (1= highest priority). Therefore, each participant had to abandon 10 statements judged less
214 important for parents. One participant declined to contribute to step 3 due to objections to the
215 20 statements selected in step 2. This resulted in the emergence of ten preferred information-
216 sharing statements from the experts (Supplementary material table 2).

217 We did not observe any obvious association between the relevance score and the
218 propensity to be abandoned, i.e. some propositions were kept by all participants although the
219 relevance score was not very high, and vice versa. For instance, statement 4 relating to the
220 temperature threshold for triggering a FS was abandoned by the majority of child neurologists
221 (7/10), although the 3 who kept this statement scored it as priority. “Degree of temperature is
222 not very important in triggering seizures, sometimes even with a very mild increase of

223 temperature, an event might occur. The highest fever necessary to cause FS is specific to the
224 individual as each child's threshold convulsive temperature varies.”

225 Three statements achieved the greatest consensus in that they were kept by all or
226 almost all participants (associated with only 2, 0, 2, and 1 abandons respectively):

227 - “FS are common: for every 100 children aged 6 months-5 years, between 3 and 5 will
228 experience one or more febrile seizures.”

229 - “In the event of a FS: keep calm, make the environment safe, place the child in the
230 recovery position, do not place anything into the mouth or between the teeth, note
231 duration and features of the seizure”

232 - “In most cases, FS spontaneously cease within 2-3 minutes, and do not require any
233 treatment.”

234 - “Call emergency services if:

235 ○ A FS lasts longer than 5 min

236 ○ rectal diazepam has been applied

237 ○ there are focal features

238 ○ there is post-ictal paresis

239 ○ the child’s general clinical condition seems impaired or symptoms are
240 prolonged (more than 5 min)”

241

242 The same three-step procedure was run with pediatricians.

243

244 **Pediatricians Step 1** (Supplementary material table 3)

245 A total of 55 statements were collected from the first round with the pediatricians. The
246 five previously identified categories were also found in the pediatricians’ proposals: FS and
247 epidemiology (mean age of occurrence, percentage of the general population with FS), possible
248 mechanisms of FS, safety measures to take in the event of recurrence and when to go to the
249 pediatric emergency department. Many statements offered reassurance, emphasizing the
250 ‘excellent prognosis’ of FS, the ‘short duration of a seizure’, and the fact that ‘children
251 experiencing FS will have normal intelligence’.

252

253 **Pediatricians Step 2** (Supplementary material table 3)

254 The 55 statements were scored in the second round from 1 to 9.3 with standard
255 deviations spreading out from 0.9 to 3.8 indicating use of the whole scale. The four best-scored
256 statements illustrate how public health messages were at the core of the content of information
257 shared at a clinic following a FS and were as follows:

- 258 - "A typical FS does not require an assessment by a neurologist nor any further
259 investigations (electroencephalogram i.e. EEG, Magnetic Resonance Imaging scan i.e.
260 MRI, etc.)"
- 261 - "General recommendations for the management of the FS in the family environment:
262 a) keep calm; b) lie the child on the floor and loosen clothing; c) remove any objects
263 nearby; d) if the child is unconscious, put him/her in lateral decubitus (side-lying
264 position); e) do not force opening of the mouth and do not try to put anything inside; f)
265 observe the type and duration of the seizure; g) do not give drugs or fluids orally. If the
266 seizure persists more than 3 minutes administer rectal diazepam, as medical
267 prescription."
- 268 - "The number of simple FS does not correlate with the risk of epilepsy nor with the risk
269 of developing cognitive disorders, therefore neither prophylaxis nor intermittent
270 strategies with benzodiazepines nor continuous antiepileptic drugs are usually
271 recommended."
- 272 - "The correct explanation on the management of fever is essential to avoid the
273 abuse/overuse of antipyretic drugs or other inappropriate and unnecessary measures
274 of intervention on fever (physical methods such as fanning, cold bathing and tepid
275 sponging). All this is aimed at reducing or removing the intrinsic fear of the fever
276 affecting the family members. Using antipyretic medication can make child feel better
277 when unwell with fever but should not be seen as useful for preventing FS. "

278 The statements associated with low-relevance score were mostly addressing the risk of
279 recurrence of FS, or the risk of epilepsy.

280

281 **Pediatricians Step 3** (Supplementary material table 4)

282 Unfortunately, incomplete data affected analysis in step 3. One expert did not
283 participate in the last round and four experts did not perform the scoring appropriately. This
284 resulted in scores from only five pediatricians being available for analysis. Based both on the
285 relevance score and on the propensity to be abandoned, 10 statements emerged from the third
286 step. Statements abandoned by at least 3 experts were not kept in the final selection
287 (Supplementary material table 4). The 10 statements selected emphasized the following (**Table**
288 **1**): FS are common, fever does not systematically cause a FS, FS generally cease
289 spontaneously, most FS do not require further investigation.

290

291 **DISCUSSION**

292 Although fever-phobia has negative consequences in terms of public health,
293 recommendations are still lacking with regard to the management of parents and carers
294 following FS and with regard to the management of subsequent episodes. Several studies
295 produced guidelines for physicians²¹⁻²⁴. Armon et al. used a Delphi-process to raise a
296 consensus-based guideline intended for physicians focusing on the management of a child
297 after a seizure²⁴. This interdisciplinary and multinational work has used a Delphi-process to
298 raise a consensus about what first key messages to share with parents following a FS.

299 Similar messages were prioritized by both sets of panelists with similar evaluation of
300 relevance however, the rankings of priority of the messages to parents were slightly different.
301 In the first step of the process, pediatricians delivered more statements about the sequence of
302 clinical signs characterizing a FS. They emphasised that FS should not be perceived as a sign
303 of an infection of the central nervous system. They highlighted the distinction between ‘simple’
304 versus ‘complex’ FS, while child neurologists did not. They also mentioned differential
305 diagnoses such as Dravet syndrome. Pediatricians gave more details about risk factors of FS
306 (such as having several FS, having a family history of FS), and the risk factors associated with
307 developing epilepsy in the future. Some participants in this group were more ‘permissive’ about
308 the need for investigations (such as MRI), but such statements were not selected in the next
309 rounds of the study. Finally, the pediatricians focused more on the management of parental
310 stress.

311 Importantly, however, in the later steps, child neurologists and pediatricians converged
312 on the main key messages to share with parents, as summarized in the 10 statements emerging
313 from both groups of panelists (**Table 1**).

314

315 Interestingly, no expert addressed the risk of change in parental behavior that might be
316 adopted after FS, such as co-sleeping⁶. However, both groups of experts described the risks
317 associated with antipyretic and antiseizure medication overuse.

318 Our study has limitations. Firstly, not all experts completed the three-step process.
319 Secondly, the views from a parent/carer group whose children experienced FS would have
320 added to the consensus reached in this study. Parental views regarding the information they
321 wish to receive as well as the accessibility of the language used e.g. 'simple FS', 'immature
322 brain', 'focal symptoms' or 'post-ictal paresis' would have been helpful. It has been shown that
323 the priorities of health care professionals can differ from those of patients and relatives²⁴. Third,
324 our study has a limited generalizability, given that it has only been run in five European
325 countries.

326 Finally, there was consensus between both groups of experts concerning the most
327 important information sharing statements even if the prioritization differed slightly. The next
328 steps will involve parent/carer groups in finalizing the information sharing statements followed
329 by a validation study of the effectiveness of these statements following an episode of FS. The
330 information would be effective if it improved understanding, decreased parental anxiety and
331 post-traumatic stress disorder and prevented the modification of usual parenting behaviours.

332

333	TABLE 1 – Key messages on febrile seizure for parents issued from a Delphi process
334	
335	1- Definition: Febrile seizures, also commonly known as febrile convulsions, are
336	epileptic seizures that occur in association with increased temperature. They are not
337	epilepsy, but are rather sensitivity to the child’s immature brain at fever.
338	2- Acknowledging parental stress: FS might appear frightening to observer but are
339	generally harmless.
340	3- A common phenomenon: Febrile seizures are common, up to 2 to 5 % of children in
341	the United States and Western Europe, and 6% to 9% of infants and children in
342	Japan, will have experienced at least one febrile seizure, simple or complex, by the
343	age of 5 years.
344	4- Recurrence: Not all illness and episodes of fever will provoke a febrile seizure.
345	5- In case of FS:
346	a. keep calm, secure site that child cannot harm itself during the seizure, apply
347	stable side position, do not apply anything into mouth or between teeth, note
348	time and character of seizure
349	b. Most FS spontaneously terminate within 2-3 minutes, not requiring any
350	treatment.
351	6- What if the FS lasts longer than 5 minutes? Call emergency if:
352	a. FS lasts longer than 5-10 min
353	b. rectal diazepam has been applied
354	c. focal symptoms, post-ictal paresis, general clinical condition is impaired/
355	symptoms prolonged
356	7- Diagnosis of febrile seizure is essentially based on history taking and physical
357	examination. Laboratory tests, EEG, neuroimaging as a routine diagnostic procedure
358	being not recommended.
359	8- Follow-up: No specialized follow-up is necessary. A consultation with your attending
360	physician is recommended to talk about this event with him.
361	9- Prognosis: The number of simple FS does not correlate with the risk of epilepsy nor
362	with the risk of developing cognitive disorders, therefore neither prophylaxis, nor
363	intermittent strategies with benzodiazepines nor continuous antiepileptic drugs are
364	usually recommended.
365	10- Prevention:
366	a. The number of simple FS does not correlate with the risk of epilepsy nor with
367	the risk of developing cognitive disorders.
368	b. Therefore, neither prophylaxis, nor intermittent strategies with
369	benzodiazepines nor continuous antiepileptic drugs are usually
370	recommended.
371	c. Using antipyretic medication can make child feel better when unwell with
372	fever but should not be seen as useful for “preventing” FS.

373
374

- d. Parents should avoid co-sleeping, which is dangerous for their child and will not prevent FS.

375 **Conflict of interest**

376

377 **The authors declare having no conflict of interest. No funding contributed to this**
378 **study.**

379

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