**Supplement 1.** Translated questionnaire.

PATIENT ID: ……………… DATE: ……………………………… INVESTIGATOR ID:

TEST WITH: □ the patient him/herself □ patient with some assistance of the carer □ the carer with the patient ’s participation □ the guardian only

METHOD: □ in person □ by phone □ via the Internet □ traditional correspondence

**M. DEMOGRAPHIC QUESTIONS**

| M.1. Age       | M.3. Location                                    |
|----------------|-----------------------------------------------|
| □ 18-29                          | □ Rural area                                  |
| □ 30-39                          | □ city up to 50,000 residents                   |
| □ 40-49                          | □ city up to 100,000 residents                  |
| □ 50-59                          | □ city up to 250,000 residents                  |
| □ 60-69                          | □ a city with over 250,000 residents            |
| □ 70 years or more               |                                               |

| M.2. Sex       | M.4. Education                                |
|----------------|-----------------------------------------------|
| □ woman        | □ elementary                                  |
| □ man           | □ junior high school                          |
|                 | □ high shool                                  |
|                 | □ higher                                      |

| M.5.3. Self-diagnosis: | YES/ NO |

**A. DIAGNOSTIC PATH**

A.1.1. When did the first symptoms occur?

A.1.2. Description of symptoms:

A.2.1. When was first diagnosis established (any diagnosis, not necessarily the correct one)?

A.2.2. What was the diagnosis?

A.2.3. Where? By whom? (physicians specialty)

A.3.1. When was subsequent diagnosis established?

A.3.2. What was the diagnosis?

A.3.3. Where? By whom?

A.4.1. When was subsequent diagnosis established? (if applicable):

A.4.2. What was the diagnosis?

A.4.3. Where? By whom?

A.5.1. When was the final diagnosis established (SLA):

A.5.2. Where? By whom?

A.5.3. Self-diagnosis: YES/ NO
B. DIAGNOSIS DELIVERY

B.1. Was it suggested that a family member / guardian could participate in the interview?
   - Yes
   - No
   - I don’t remember
   - Does not apply (there was such a person)

B.1.1. Do you think it is good to have someone close present during the diagnosis delivery?
   - Yes
   - No
   - I have no opinion

B.2. The conversation took place:
   - In the doctor’s office
   - In the hospital room
   - In the hospital corridor / clinic
   - Other, what: …

B.3. Was the diagnosis communicated to you in an understandable way?
   - Yes
   - No
   - Hard to say

B.4. How was the course of the disease / the prospect of living with the disease described to you?

B.5. Which of the following tests were performed prior to diagnosis:
   - EMG
   - Magnetic resonance imaging
   - Genetic
   - Neurological
   - Other, what

B.6. During the delivery of the diagnosis, did you hear anything that was particularly helpful, uplifting or reassuring?
   - Yes Go to question B.6.1.
   - No Go to question B.7.
   - I don’t remember Go to question B.7.

B.6.1. What words and / or behaviors of the doctor (other members of the healthcare team) were particularly supportive, helpful, uplifting or reassuring for you?

B.7. During the diagnosis, did you hear anything that was unnecessary, inappropriate or soulless?
   - Yes Go to question B.7.1.
   - No Go to question B.8.
   - I don’t remember Go to question B.8.

B.7.1. What words and / or behaviors of the doctor (other members of the medical staff) were, in your opinion, unnecessary, inappropriate, soulless?
B.8. During the interview during which you were given the diagnosis, did you receive (if any of the following items are indicated, go to B.9., If not go to B.10):
  o leaflets / other printed material about the disease
  o link to the website of the patients' association / foundation / support group
  o contact to patient' association / foundation / support group
  o contacting a doctor specializing in ALS treatment (including clinical trials etc.)
  o I have not received any material about the disease
  o I do not remember
  o Other: ….

B.9. Which materials and sources of information turned out to be particularly helpful in the first months after diagnosis?
  o leaflets / other printed material about the disease
  o link to the website of the parents' association / foundation / support group
  o contact to parents' association / foundation / support group
  o contacting a doctor dealing with ALS treatment (including experimental ones)
  o I do not remember
  o Other:

B.10. What kind of information did you receive during the interview during which the diagnosis was delivered?
  o about the mechanism and causes of the disease
  o about the treatment options for ALS
  o about rehabilitation (physiotherapy, speech therapy, neurological rehabilitation)
  o about the options of psychological support
  o about the options of social security assistance
  o about the domestic ventilation program
  o on experimental therapies based on stem cells
  o about experimental drug therapies
  o on how to deal with the disease in everyday life
  o None of the above
  o Other:

B.11. In retrospect, do you think that some information that would be helpful was missing?
  o Yes (insert below)
  o No Go to question 12.

B.12. When do you think people with ALS should be informed about their disease:
  o only after getting a complete diagnosis
  o in a situation where the suspicion of disease is well-grounded
  o whenever there is a suspicion of the disease

B.13. Please share any other comments and thoughts on the manner in which you received the diagnosis.