LISEF
LOCKED-IN SYNDROME EUROPEAN FEDERATION

Dear,

The locked-in syndrome european federation (LISEF) organizes a survey and information campaign..

Our common and dedicated efforts and commitment ensure an important contribution to the life improvment of people with LIS. Our scope is to inform and provide evidence to institutions, the world of medicine as well as families and population.
We will use the information you provide for statistical purposes only and we will hold them as strictly confidential.

We greatly appreciate your collaboration to these studies and invite you to fill and return the questionnaire enclosed.

We thank you for your support.

With very best regards

LISEF scientific committee

contact@lockedinsyndrome.eu

Place and date _____

Signature _____

Enclosure: document of legal tutor/disability trustee

Protocol n._____(association)

European questionnaire on Locked-In Syndrome condition

1. Personal information

Name:…… First name: …… Date: ……/……/……
Date of birth: ……/……/…… Place of birth:…….. Gender: Male (…) Female (…)
Address:……
@mail:……
Telephone:…… Mobile phone:……
The questionnaire is filing in by: You(…) Spouse(...) Companion(...) Parents(...) Child(...) Caregiver(...) Other(.....)

A. Way of life

- Place of living: Hospital (…) Rehabilitation center(…) Rest/nursing home(…) Home(…) Other(.....)
- Married (…) Single(…) Separated(…) Divorced(…) Widow(…) Partner(…) Profession before the accident: ……
- Children: No(…) Yes(…) Male age (…, …, …, …, …, …) Female age (…, …, …, …, …, …)
- Where do your children live - before LIS condition:…… after LIS condition:……
- Educational level: None (…), Primary school (…), Secondary school (…), College (…), University (…)
- Religiosity: No (…) Yes (…) Practicing (…), Non-practicing (…)
- Did you lose your legal authority since the accident? No (…) Yes (…) If yes, specify:.....
- Did this loss caused impediments? No (...) Yes(...) If yes, specify.....
- Net monthly household income: Less than 10.000€(…) 10.000-25.000€(…) 25.000-40.000€(…) 40.000-60.000 €(…) More than 60.000 €(…)
- Total pension contribution……€ Public medical care (…) Private origin (…) Invalidity pension ……€ Accompanying pension ……..€ Visually impaired pension……..€ Other……..€
- If you are currently living at home, when did you come back after the accident ……/……/ …… Do you live with: Spouse (...) Companion (...), Parents (…), Other family members (…), Other(.....)
- If you are not living at home, could you specify the reasons (family context, lack of human aids, financial difficulties):…… ……
- Regardless your place of living (hospital, rehabilitation center, rest/nursing home, home) : What is the total monthly cost ……€ What is the total monthly cost for caregivers (not medical caregiver): ……€ How many hours/week:…… All of your costs are covered by your health insurer Yes (…), No(…) Which ones:……...Own contribution to the costs……€
- Do you receive a funding or a reimbursement for home care worker No (…) Yes (…) If Yes……..€
- Do you have special equipment: wheelchair (…) bathroom(…) medical bed(…) pressure sore cushion(…) adapted car(…)Other(……). Specify origin and costs of funding for each equipment:…… ……
- Are you experiencing financial hardship to acquire some equipment: No (…) Yes (…) Specify:……..

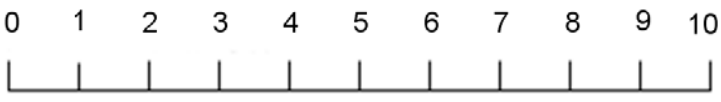
2 Clinical picture

2-A/ Diagnosis.

Date of the accident: ……/……/……Etiology: Ischemic stroke (…), Hemorrhagic stroke(…) , Trauma(…), Other (……)
Date of recovery of consciousness: ……/……/…… Diagnosis of locked-in syndrome ……/……/……
Who was the first person who realized that you were conscious and that you could communicate via eye movements?
Physician (…), Paraclinical professional (psychologist, speech therapist, physio/occupational therapist) (…) Family (…)
Other(.....) Time elapsed between brain insult and LIS diagnosis:……

2-B / General clinical picture

- Weight before the accident …….Kg - After the accident …….Kg
- Do you feel pain? No pain or discomfort (…), Moderate pain or discomfort (…) Extreme pain or discomfort (…)
- How was your physical pain during the two last week - 0 = no pain → 10 = unbearable/excruciating pain)



- Presence of pressure sores: No (…) Yes (…) Specify (location, deepness/grading)……
- Date of appearance? ……/……/……
- Ankylosis No (…) Yes (…) Which joint(s)? …… Complete (…) Partial (…) More than 50% range of passive movement (…) Less than 50% range of passive movement (…)
- Endoscopic feeding tube: Gastrostomy (…) Jejunostomy (…) Date of placement: ……/……/…… Date of removal ……/……/19…… Still in place (…) Never had (…)
- Tracheostomy: Date of placement: ……/……/…… Date of removal ……/……/…… Still in place (…) Never had (…)

(Name : ……..) Type: with inner cannula (double-cannula) (…), cuffed cannula (…), speech/fenestrated cannula (…)

- Recovery of some limb mobility? No (…) Yes (…) Please list all movements that you are able to perform (e.g. head, hand, fingers)……

Are they useful in daily living? No (…) Yes (…) Specify (eg: eating, driving the wheeling chair)……
……..

- The accident caused problems with vision/acuity: No (…) Yes (…) Double vision (…) Nystagmus (…)

Lower visual acuity: far (…), close (…), reduced field of vision (…) Other (……..)

Did you notice an evolution since the accident? No (…) Yes (…)

Improvement: ……/……/…… Specify?……

Impairment: ……/……/…… Specify?.....

- The accident caused problems with hearing: No (…) Yes (…) If yes:
  - Lower acuity: No (…) Yes (…) If yes, one side (…) from both sides (…)
  - Deafness: No (…) Yes (…) If yes, from one side (…) from both sides (…)
  - Sound distortion: No (…) Yes (…) If yes, from one side (…) from both sides (…)
  - Hearing of unfamiliar sounds: No (…) Yes (…), If yes, voices (…), tinkling (….), hissing (….)
  - Other, specify ……..

Did you notice an evolution since the accident? No (…) Yes (…)

Improvement: ……/……/…… Specify?……

Impairment: ……/……/…… Specify?.....

- Do you have a motorized wheelchair ? No (…) Yes (…) If yes, do you drive it by yourself? No (…) Yes (…)

Through which movements ?…… Through which device (e.g. joystick) ? ……

3 COMMUNICATION

- Even in a short period, was your communication mainly (> 50% time) through eye movements? : No (…) Yes (…)
  Currently, how do you usually expressed "Yes/ No" answers? Eyes (……)
  Head (……) Hand (……)
  Device (……) Other (……)

Which method of communication are you currently using most frequently? : Code using eyelid blinks or vertical eye movements (…) Alphabetical communication (…) Vowel and consonant method (…) Alphabetical system using a grid of letters (…)

Device (…) Specify……

- If oral communication, specify how do you communicate: I'm able to pronounce : words (…) sentences
- Do you use a computer or another electronic assistive technology to communicate (…)
  Computer type, brand: ……
  Software type, brand:……
  Software link versus computer, which one:……

How do you control your assistive technology (computer/electronic): Eye tracking (…) Head command (…) Finger (…) Other, Specify……

Are you using: Vocal synthesizer (…) Specify…….. Vocal link versus computer (…) Specify……..

Other (…) ……

Are your computer based communication technology effective? No (…) Yes (…) If No, why?.....
……

Are you mostly using a "computer based communication technology" to communicate? No (…) Yes (…) If yes, for daily life (…) for internet/email (…) Other (……..)

4 Care

Length of stay in hospitals (weeks): ICU/stroke unit (…..) neurology (…..) "coma arousal unit"(…..) neuro rehabilitation (…..) classical rehabilitation unit (…..) non rehabilitation unit (…..) Other (……..)

Where did you get the most intensive rehabilitation: ICU/stroke unit (...) neurology (...) "coma arousal unit"(...) neuro rehabilitation (…) classical rehabilitation unit (…) non rehabilitation unit (…) Other (……..)

Establishment name and city where you get those rehabilitation cares : ……
……..

Describe the rehabilitation you got in this place:

Speech therapy/logopedy (…) How many times a week? (…) How long each session (…… minutes)
Physiotherapy (…) How many times a week? (…) How long each session (…… minutes)
Occupational therapy (…) How many times a week? (…) How long each session (…… minutes)
Respiratory physiotherapy (…) How many times a week? (…) How long each session (…… minutes)
Psychological aid (…) How many times a week? (…) How long each session (…… minutes)
Neuropsychology rehabilitation (…) How many times a week? (…) How long each session (…… minutes)

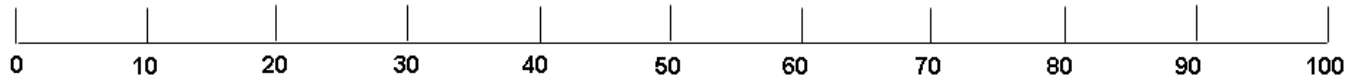
Date of return from rehabilitation center to the leaving place (home or other place of living): ……/……/……

Describe the rehabilitation you get in the place you are currently living:

Speech therapy/logopedy (…) How many times a week? (…) How long each session (…… minutes)
Physiotherapy (…) How many times a week? (…) How long each session (…… minutes)
Occupational therapy (…) How many times a week? (…) How long each session (…… minutes)
Respiratory physiotherapy (…) How many times a week? (…) How long each session (…… minutes)
Psychological aid (…) How many times a week? (…) How long each session (…… minutes)
Neuropsychology rehabilitation (…) How many times a week? (…) How long each session (…… minutes)
Nurse How many times a day ? (…) How many times a week (…)
What cares the nurse bring to you ?.....

5 Quality of life – Subjective well being

We would like you to indicate on this scale how good or bad your own health is today.



Worst imaginable health state **Best imaginable health state**

	Yes	Rather Yes	Rather No	No
(1) I move around my living quarters as I feel necessary.	☐	☐	☐	☐
(2) I move around my community as I feel necessary.	☐	☐	☐	☐
(3) I am able to take trips out of town as I feel are necessary.	☐	☐	☐	☐
(4) I am comfortable with how my self-care needs (dressing feeding toileting bathing) are met.	☐	☐	☐	☐
(5) I spend most of my days occupied in work activity that is necessary or important to me.	☐	☐	☐	☐
(6) I am able to participate in recreational activities (hobbies crafts sports reading television games computers etc.) as I want to.	☐	☐	☐	☐
(7) I participate in social activities with family friends and/or business acquaintances as is necessary or desirable to me.	☐	☐	☐	☐
(8) I assume a role in my family which meets my needs and those of other family members.	☐	☐	☐	☐
(9) In general I am comfortable with my personal relationships.	☐	☐	☐	☐
(10) In general I am comfortable with myself when I am in the company of others.	☐	☐	☐	☐
(11) I feel that I can deal with life events as they happen.	☐	☐	☐	☐

Mobility ☐ I have no problems in walking about ☐ I have some problems in walking about ☐ I am confined to bed
Self-Care ☐ I have no problems with self-care ☐ I have some problems washing or dressing myself ☐ I am unable to wash or dress myself
Usual Activities (e.g. work, study, housework, family or leisure activities) ☐ I have no problems with performing my usual activities ☐ I have some problems with performing my usual activities ☐ I am unable to perform my usual activities ☐
Anxiety/Depression ☐I am not anxious or depressed ☐ I am moderately anxious or depressed ☐ I am extremely anxious or depressed
Suicidal thoughts ☐never ☐occasionally ☐often
Consideration for euthanasia ☐never envisaged ☐envisaged in the past but not now ☐wanted now
Before LIS, in case of cardiac arrest, ☐I had the desire to be resuscitated ☐I had the desire not to be resuscitated
Now, in case of cardiac arrest, ☐I want to be resuscitated ☐I don't want to be resuscitated

Questions about your life environment

Evaluation of your town	**Poor**	**Bad**	**Good**	**Excellent**	**None**	**Out of order**
(1) Welfare domicile support	☐	☐	☐	☐	☐	☐
(2) Residential house facilities	☐	☐	☐	☐	☐	☐
(3) Access to bureaucracy connected to the disease (information, timing, process)	☐	☐	☐	☐	☐	☐
(4) Transport (school, education, work)	☐	☐	☐	☐	☐	☐
(5) Work integration	☐	☐	☐	☐	☐	☐

Evaluation of medical/welfare aspects and support	**Poor**	**Bad**	**Good**	**Excellent**	**None**
(1) Admittance to rehabilitation centres when back at your home	☐	☐	☐	☐	☐
(2) Obtaining certificate of disability	☐	☐	☐	☐	☐
(3) Aids supply (eg wheelchair, electrical bed…) by health district	☐	☐	☐	☐	☐
(4) Psychological aid	☐	☐	☐	☐	☐
(5) Dietetics and nutrition service	☐	☐	☐	☐	☐
(6) Home care worker	☐	☐	☐	☐	☐

5 Relations with the national locked-in syndrome association

Which are your expectations from our association in terms of individual support?
(ie. advice, financial support, psychological aid, therapy, communication, legal assistance, …)

……

……

……

How our association could best help you?

……

……

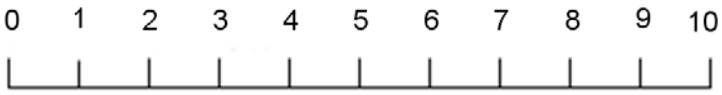
……

Would you like to be inserted in our mail list? (receive news via internet)? No (…) Yes (….)

THE FOLLOWING SECTION IS ONLY FOR THE CAREGIVER IN CASE YOU ARE LIVING AT HOME
THE ANSWERS WILL BE KEPT ANONIMOUS

Male (…) Female (…) Name:……First name: ……
Date of birth: ……/……/…… Since how many months do you brings cares to the LIS person you are nearby
Which is your relationship with the person LIS? Husband (…) Wife (…) Son (…)/Daughter (…) Parent (…) Oncle/Aunt (…) Cousin (…)None (…)Other (……..)
Who has chosen current place of living? The person LIS (…) Husband (…) Wife (…) Son (…)/daughter (…) Parent (…) Oncle/Aunt (…) Cousin (…)None (…)Other (……..)
Are you taking care of the patient every day? No (…) Yes (…) if Yes, how many hours a day? ……
Do you have a psychological support? No (…) Yes (…)

Are you satisfied with the support you receive? (0 absolutely NO, 10 fully satisfied)



Which would be your expectations?
……
……
……

Do you think that,
Your care give is always the result of a real choice? No (…) Yes (…)
It is overwhelming but you are happy No (…) Yes (…)
It is overwhelming and an inevitable choice ? No (…) Yes (…)

Anxiety/Depression ☐ I am not anxious or depressed ☐ I am moderately anxious or depressed ☐ I am extremely anxious or depressed

THANK YOU