Kleine-Levin Syndrome Questionnaire
Stanford Center for Sleep Disorder
Stanford University

CONFIDENTIAL

Foreword

Thank you for taking part in our research on Kleine-Levin syndrome (KLS). This questionnaire is aimed at better characterizing KLS symptoms and looking for commonalities among patients. It is a very important part of the research. It is a long and totally confidential questionnaire, so please take as much time as you need to complete it and to come back the next day if needed, especially for the sections at the end of the questionnaire. Do not skip any question. For some questions that refer to what happened during KLS episodes, you may need the assistance of the person(s) that have observed your sleep and overall behavior.

If you think that some minor or major points of your disease have not been addressed or addressed insufficiently here, please do not hesitate to add further comments at the end of the questionnaire. We appreciate any details that can help us achieve a better understanding of the disease.

SECTION I: Administrative information

DATE COMPLETED: ______________________________

NAME____
Last First Middle

ADDRESS____
Street address City

____
State/province Postal Code Country

TELEPHONE: (____)______________________(____)________________(____)____________________
Home Work Cellular

E- Mail address: ____

AGE: ______ BIRTH DATE: ____/____/______ SEX: Male ☐ Female ☐
month/ day / year

OCCUPATION____________________ Height ____/____ Feet/Inches or Meter/Cm (please circle)

Weight ______ pounds or kg (please circle)

DIAGNOSIS
- ☐ Kleine-Levin syndrome
- ☐ Parent of a patient with Kleine-Levin syndrome
- ☐ Other Sleep Disorder Diagnosis (not Kleine-Levin syndrome) ____________________
- ☐ No Sleep Disorder Diagnosis____

Was KLS or Sleep Disorder diagnosed by: ☐ MD ☐ Yourself (self-diagnosis)?

CURRENT PHYSICIAN (who treats your KLS and maintains your medical history and treatment records)
NAME: ____

ADDRESS: ____
Street address City

____
State/province Postal Code Country

TELEPHONE (____)___________________________E- Mail address: ____________________________

OTHER PHYSICIANS (if you were hospitalized, or if a specialist was taking care of you)
NAME: ____

ADDRESS____
Street address City
____
State/province Postal Code Country
TELEPHONE (___)____

OTHER PHYSICIANS (if you were hospitalized, or if a specialist was taking care of you)
NAME: ____

ADDRESS____
Street address City
____
State/province Postal Code Country
TELEPHONE (___)____

Please check if you have you ever had a polysomnogram (sleep study): YES ☐ NO ☐

If yes, please indicate the location where your sleep study was done.
Name: ____

SLEEP CENTER/Hospital ____

ADDRESS ____
Street address City
____
State/province Postal code Country

TELEPHONE (___)____________________ DATE OF STUDY____________________

SECTION II: Family history

In this research study, we will determine your HLA group. This genetic group, located on white blood cells, is a characteristic of our individuality (it is identical between true twins), but also of our ethnicity (some HLA groups are more frequent in Asian people, for example). It is important to determine if one HLA group is more frequent in subjects with KLS than in subjects without KLS, within the same ethnic group. Hence the questions in this section relative to your ethnic origins, back to your grandparents.

1. Where were you born? ____
City State/province Country

2. With which of the following major ethnic groups do you identify?
Check all that apply and specify the country or countries of origin of yourself and forebears for each group checked. For example, if you consider yourself Asian, specify whether Chinese, Korean, etc. If you consider yourself American, specify your family's country of origin prior to immigration to the United States. If you are in doubt, please give your best guess and place a question mark (?) next to your answer.

☐ Black ____________________
☐ Pacific Islander ____________________
☐ Caucasian (white European)____________________
☐ Jewish (specify Ashkenazi or Sephardic)____________
☐ Native American ____________________
☐ Hispanic____________________
☐ Asian ____________________
☐ Other (specify) ____________________

Please answer questions 3-10 in the same way.

3. Where was your mother's mother born? ____

4. With which of the following major ethnic groups does/did your mother's mother identify? (Check all that apply and specify the country/countries of origin for each group checked.)

☐ Black ____________________
☐ Pacific Islander ____________________
☐ Caucasian (white European)____________________
☐ Jewish (specify Ashkenazi or Sephardic)____________
☐ Native American ____________________
☐ Hispanic____________________
☐ Asian ____________________
☐ Other (specify) ____________________

5. Where was your mother's father born? ____

6. With which of the following major ethnic groups does/did your mother's father identify? (Check all that apply and specify the country/countries of origin for each group checked.)

☐ Black ____________________
☐ Pacific Islander ____________________
☐ Caucasian (white European)____________________
☐ Jewish (specify Ashkenazi or Sephardic)____________
☐ Native American ____________________
☐ Hispanic____________________
☐ Asian ____________________
☐ Other (specify) ____________________

7. Where was your father's mother born? ____

8. With which of the following major ethnic groups does/did your father's mother identify? (Check all that apply and specify the country/countries of origin for each group checked.)

☐ Black ______________________ ☐ Native American ______________
☐ Pacific Islander ______________________ ☐ Hispanic ______________
☐ Caucasian (white European)____________ ☐ Asian ______________
☐ Jewish (specify Ashkenazi or Sephardic)__________ ☐ Other (specify) ______________

9. Where was your father's father born? ____

10. With which of the following major ethnic groups does/did your father's father identify? (Check all that apply and specify the country/countries of origin for each group checked.)
☐ Black ______________________ ☐ Native American ______________
☐ Pacific Islander ______________________ ☐ Hispanic ______________
☐ Caucasian (white European)____________ ☐ Asian ______________
☐ Jewish (specify Ashkenazi or Sephardic)__________ ☐ Other (specify) ______________

11. How many siblings (with same parents) do you have? Total: ____ Sisters: ____ Brothers: _____

12. Did any members (grandparents, parents, siblings, children, cousins) of your family suffer from past or present sleep disorders? YES ☐ NO ☐
If yes, please check appropriate disorder and indicate relative (father, grandmother, etc).

☐ Insomnia ______________ ☐ Restless legs syndrome ______________
☐ Narcolepsy ______________ ☐ Kleine-Levin syndrome ______________
☐ Hypersomnia ______________ ☐ Sleepwalking ______________
☐ Sleep apnea ______________ ☐ Other sleep disorder ______________

13. Has anyone in your family (parent, grandparent, sister/brother, son/daughter) been diagnosed with any of the conditions below? YES ☐ NO ☐
If yes, please check the appropriate condition(s) and indicate relative.

☐ Mild/moderate depression________ ☐ Alzheimer's disease_____________
☐ Severe depression_____________ ☐ Stroke_____________
☐ Suicide attempt_____________ ☐ Multiple sclerosis_____________
☐ Parkinson's disease____________ ☐ Seizure or epilepsy_____________
☐ Lupus_____________ ☐ Ankylosing spondylitis _____________
☐ Juvenile onset Type I diabetes ____________ ☐ Attention Deficit/hyperactivity Disorder________

14. Is there a history of other significant medical or genetic conditions in your immediate family? YES ☐ NO ☐
Please detail the disease(s) in the family and indicate the member(s) affected:

____
____
____
____
____

---

15. Are both of your parents alive? YES ☐ NO ☐
If YES, might both of your parents be willing to submit a blood sample? YES ☐ NO ☐
If YES, will both of your parents submit a blood sample with yours? YES ☐ NO ☐
If YES, may we contact your parents? YES ☐ NO ☐

ADDRESS (father)____
Street address City

____
State/province Postal code Country

TELEPHONE (___)________________________E- Mail address: ________________________________

ADDRESS (mother, if different from father)____
Street address City

____
State/province Postal code Country

TELEPHONE (___)________________________E- Mail address: ________________________________

Section III: History of Kleine-Levin syndrome (KLS)

For this section, do not hesitate if you do not remember well, to ask for details from your family members who were present at the time of your KLS onset.

1. When did your first symptoms of KLS occur? DATE _______/______(month/year)

1. How old were you when it occurred? ________ years

1. In which city, state and country were you when KLS onset occurred?________________________

1. Do you remember any specific events occurring before your KLS onset?
YES ☐ NO ☐ DON'T KNOW ☐

If yes, please explain: ________________________

5. You will find below a list of conditions that have sometimes been reported just before the first KLS episode in patients. Please check the condition(s) that apply in your case.

☐ Fever
☐ Flu or flu-like symptom
☐ Throat infection
☐ Encephalitis
☐ Gastroenteritis
☐ Cold
☐ Use of alcohol
☐ Use of marijuana
☐ Use of nitrous oxide (laughing gas)
☐ Use of another recreational drug
☐ Use of a medical drug (specify below)
☐ Travel (explain below)
☐ Infection in a person you were in contact with
☐ No particular condition
☐ Other________________________
☐ Headache
☐ Head trauma (explain below)
☐ Physical exertion
☐ Unusual stress
☐ Dentist anesthesia
☐ General anesthesia
☐ Surgery
☐ Vaccine
☐ First menarche
☐ Menses
☐ Sleep deprivation
☐ Jet lag
☐ High altitude
☐ Sun/Heat stroke

If you checked one or several of these conditions, could you give more details (such as name of the triggering drug or country where you traveled, or type of exercise or stress, if it was the case).

____

6. What exactly were your first KLS symptoms?

____
____
____
____

7. Was the KLS onset: Sudden (over hours) ☐ Progressive (over days) ☐ Do not know ☐

   Comments:____
   ____
   ____

8. How long did your first KLS episode last? ____________________________(days/weeks/months)

9. Did your first KLS episode end:
   Abruptly (over hours) ☐ Progressively (over days) ☐ Do not know ☐

10. Did a special event or treatment help in ending your first or other KLS episodes?
    YES ☐ NO ☐ DON'T KNOW ☐

Please detail what event or treatment helped, even if it seems trivial or amazing

____
____
____
____

11. How many episodes of KLS have you experienced? ___________________________________

12. Do you consider that you are now cured of KLS?
    YES ☐ NO ☐ DON'T KNOW YET ☐

13. What is the duration of your KLS episodes (please circle if it is days, weeks or months)?
    Maximum: ______ days/weeks/months Minimum: _____ days/weeks/months
    Average: _____ days/weeks/months

Any comments on the duration of your KLS episodes?

____
____
____

14. Did you observe any trends in subsequent KLS episodes over time (i.e. change in length of individual episodes or difference in time interval between episodes)?

____
____
____

15. What is the time interval between two KLS episodes (please circle if it is days, weeks or months)?
Maximum: ___________ week/month/year Minimum: _________ week/month/year
Average: ____________ week/month/year

16. How long ago was your last KLS episode?

- ☐ within the past week
- ☐ within the past month
- ☐ within the past three months
- ☐ more than 2 years ago
- ☐ within the past six months
- ☐ within the past year
- ☐ within the past 2 years

17. Could you please indicate the date (month and year) of your three last episodes?

____

____

____

18. How much school (or work) time did you miss because of your KLS episodes?

____

____

19. Since KLS onset, did you experience decreased academic or work performance?

YES ☐ NO ☐ DON'T KNOW ☐

If yes, please give some details about these changes in academic /work performance_______________

____

____

____

20. You will find below a list of conditions that have sometimes been reported just before subsequent KLS episodes in patients. Please check the condition(s) that apply in your case.

- ☐ Fever
- ☐ Flu or flu-like symptom
- ☐ Throat infection
- ☐ Encephalitis
- ☐ Gastroenteritis
- ☐ Cold
- ☐ Use of alcohol
- ☐ Use of marijuana
- ☐ Use of nitrous oxide (laughing gas)
- ☐ Use of another recreational drug
- ☐ Use of a medical drug
- ☐ Travel
- ☐ Infection in a person you were in contact with
- ☐ No particular condition
- ☐ Other ____
- ☐ Sun/Heat stroke
- ☐ Head trauma
- ☐ Physical exertion
- ☐ Unusual stress
- ☐ Dentist anesthesia
- ☐ General anesthesia
- ☐ Surgery
- ☐ Vaccine
- ☐ First menarche
- ☐ Menses
- ☐ Sleep deprivation
- ☐ Jet lag
- ☐ High altitude
- ☐ Headache

21. After an episode ends, how much do you remember about what occurred during that KLS episode?

☐ Nothing ☐ Vague recollection ☐ Moderate recollection ☐ Complete recollection

Comments:____

____

____

22. How long is your sleep duration during KLS episodes (whatever the episode), on a 24-hour basis?

Maximum: _____ hours Minimum: _____ hours Average: _____ hours

23. Did you observe a change in the duration of excessive sleep duration in subsequent KLS episodes over time?

YES ☐ NO ☐ DON'T KNOW ☐

If yes, please detail: ____

____

____

24. How long (days, weeks) did the symptoms of <u>hypersomnia</u> (excessive sleep) last during your KLS episodes(whatever the episode) ?

Maximum: _______ days/weeks/months Minimum: _______ days/weeks/months

Average: _______ days/weeks/months

<u>During a KLS episode</u>:

25. Is it difficult for others to awaken you from sleep? YES ☐ NO ☐ DON'T KNOW ☐

26. Do you remember experiencing intensive dreaming? YES ☐ NO ☐ DON'T KNOW ☐

27. Have you ever awakened and found you were unable to move (paralyzed)?

YES ☐ NO ☐ DON'T KNOW ☐

28. Have you ever imagined, at time of the first episode or during following episodes, that you saw or heard people, animals, objects or frightening events under the following circumstances?

☐ When you fall asleep abruptly ☐ When you take a nap
☐ When you wake up in the morning ☐ When you are drowsy
☐ When you wake up during the night ☐ I have never experienced such symptoms

29. At the end of a KLS episode, do you experience insomnia?

☐ Sometimes Frequently ☐ Never ☐

30. Any other comment on your sleep symptoms? ____________________________________

____

The following questions 31-57 still refer to your symptoms and behavior <u>during a KLS episode</u>

31. Do you have difficulty speaking? YES ☐ NO ☐ DON'T KNOW ☐
Please detail the type of difficulty you experience, with examples: ______________________

____

____

32. The following types of disturbed speech have been described in some patients with KLS. Please check the adjective(s) that apply to your speech during some of your KLS episodes (as compared to your usual speech when not in a KLS episode.

☐ mute
☐ monosyllabic
☐ slow in speaking
☐ slow in answering
☐ childish
☐ no disturbed speech
☐ slurred
☐ limited vocabulary
☐ repetitive
☐ using inappropriate words
☐ searching words
☐ other ______________________

33. Have you ever lost the sense of time? YES ☐ NO ☐ DON'T KNOW ☐

34. Have you ever lost your correct perception of space? YES ☐ NO ☐ DON'T KNOW ☐

35. Did you ever have difficulty concentrating? YES ☐ NO ☐ DON'T KNOW ☐

36. Were your motor skills impaired? YES ☐ NO ☐ DON'T KNOW ☐
Please give an example ______________________________________

____

____

37. Did you have difficulty reading? YES ☐ NO ☐ DON'T KNOW ☐
If yes, please detail (read less rapidly, read without remembering, etc): ____________________

____

____

38. Did you have memory disturbances ? YES ☐ NO ☐ DON'T KNOW ☐
Please give an example ______________________________________

____

____

39. Did you have difficulty making a decision? YES ☐ NO ☐ DON'T KNOW ☐
Please give an example ______________________________________

____

____

40. Did you have difficulty in performing two mental tasks simultaneously (for example speaking and reading at the same time)?

YES ☐ NO ☐ DON'T KNOW ☐

Please give an example ______________________________

41. Do you have an altered perception of your environment?

YES ☐ NO ☐ DON'T KNOW ☐

42. Below is a list of words used by some KLS patients to describe symptoms of altered perception. Please check the box(es) that is/are the closest to your own feelings

- ☐ objects seem to be a long way off
- ☐ voices seem distant
- ☐ feeling of being in a dream
- ☐ feeling of de-realization/unreality
- ☐ splitting between mind and body
- ☐ altered sense of smell
- ☐ no altered perception
- ☐ disconnection with the environment
- ☐ "wrong" perception
- ☐ nightmarish perception of the environment
- ☐ being "underwater"
- ☐ altered sense of taste
- ☐ other ______________________________

Please give an example or any comment you want for this point______________________________

43. Have you ever suffered from headaches during an episode? YES ☐ NO ☐

44. Have you ever had photophobia (fear of/hypersensitivity to bright light) during an episode?

YES ☐ NO ☐

45. Have you ever felt hypersensitive to noise during an episode? YES ☐ NO ☐

46. Have you ever had nausea or vomiting during an episode? YES ☐ NO ☐

47. Have you ever had hot flushes or reddening on your face during an episode? YES ☐ NO ☐

48. Have you ever had increased sweating during an episode? YES ☐ NO ☐

49. During an episode, have you ever experienced some changes in your eating behavior?

YES ☐ NO ☐

Please give an example ______________________________

50. Below is a list of abnormal eating behavior reported by some patients with KLS. Please check all box(es) that apply in your case (as compared to your normal way of eating while not in a KLS episode)

- ☐ I eat increased amounts of food
- ☐ I eat food that I would otherwise refuse
- ☐ I eat automatically
- ☐ I feel an increased appetite
- ☐ I eat what is in front of me
- ☐ I gain weight during an episode (gain: ______lb)
- ☐ my appetite for salted food is increased
- ☐ no change in eating behavior
- ☐ my appetite for sour foods is increased
- ☐ my appetite for sweet foods is increased
- ☐ I actively search for food
- ☐ my appetite is decreased
- ☐ I lose weight (loss: ______lb)
- ☐ I drink more
- ☐ I cannot stop eating
- ☐ other ___________________________

(Weight gain/loss: the greatest for any given episode)

51. During an episode, have you ever had some other behavioral disturbances?

YES ☐ NO ☐ DON'T KNOW ☐

Please give an example ____

____

____

52. Below is a list of behavioral disturbances reported by some patients with KLS. Please check all box(es) that apply in your case (as compared to your normal behavior while not in a KLS episode)

- ☐ I am more irritable
- ☐ I am more aggressive
- ☐ I am less polite
- ☐ I sing compulsively (cannot stop)
- ☐ I write compulsively (cannot stop)
- ☐ No behavior disorder
- ☐ I wash my hands compulsively (cannot stop)
- ☐ I count compulsively (cannot stop)
- ☐ I communicate less with my friends and family
- ☐ I am apathetic
- ☐ I neglect my personal hygiene
- ☐ Other behavior disorder___________________

53. During an episode of KLS, have you ever experienced changes in your sexual drive?

YES ☐ NO ☐ DON'T KNOW ☐

Please give an example____

____

____

____

54. Below is a list of sexual disturbances reported by some patients with KLS. Please check all box(es) that apply in your case (as compared to your normal behavior while not in a KLS episode).

- ☐ hypersexuality
- ☐ decreased sexuality
- ☐ overt masturbation
- ☐ obscene language
- ☐ no sexual behavior disorder
- ☐ fondling genitalia
- ☐ exposing oneself
- ☐ make unwanted sexual advances
- ☐ increased masturbation
- ☐ other sexual disorder_______________

55. Have you ever experienced psychological changes during (or at the end of) an episode of KLS?
YES ☐ NO ☐ DON'T KNOW ☐

Please give an example ____

56. Below is a list of psychological disturbances reported by some patients with KLS. Please check all the box(es) that apply in your case (as compared to your normal personality while not in a KLS episode).

- ☐ depressed mood/depression
- ☐ hallucinations
- ☐ frustration
- ☐ agitation
- ☐ no psychological disorder
- ☐ delusion (false ideas about people, things)
- ☐ excitation, increased mood
- ☐ irritability
- ☐ increased anxiety
- ☐ other psychological disorder______________

57. Did your psychological disturbance make it necessary for you to be hospitalized in a psychiatric ward YES ☐ NO ☐

If yes, for how long? ____

SECTION IV: Personal medical history, aside from Kleine-Levin syndrome

1. Do or did you suffer from any medical problem, other than KLS? YES ☐ NO ☐
Please list all your medical conditions, other than Kleine-Levin syndrome:

____
____
____
____
____

2. Please check if you have a medical history of any of the following and explain.

☐ Abnormality at your birth______________________________
☐ Your birth being difficult______________________________
☐ Trouble in development (e.g. delayed walk, speech, reading)
☐ Surgery_______________________________________
☐ Migraine
☐ Allergy
☐ Seizure
Other: ____
____
____

3. Are you regularly using a medication (NOT for Kleine-Levin syndrome)? YES ☐ NO ☐
Please detail your past and current medication [specify not for KLS], the name of the drugs you used, and the disease or condition requiring their prescription.

____
____
____
____
____

4. Are you …? Left-handed ☐ Right-handed ☐ Both ☐

5. At what age did you enter puberty (whether you are a man or a woman)? ______________years

6. For women :

Age at menarche (first period): _________

Please check if your cycles/menses are
☐ Regular
☐ Irregular

If you are now using an oral contraceptive, please check if your cycles before taking it were
☐ Regular
☐ Irregular

SECTION V: Treatments used for reducing KLS symptoms or number of episodes

Listed below are medications that may be used to treat excessive sleepiness, other KLS symptoms or are aimed at reducing the number of relapses/episodes. Please check in the table all medications that you have ever used for your KLS symptoms, and use the spaces to add during which episode(s), and duration of treatment] or add other medicines not listed. Next page is space to comment on effects of these medications. Do not include vitamins or supplements here.

Generic name	**Brand name**	**Yes**	**No**	**Don't know**	**During which episode, and for how long?**
Modafinil	Provigil	☐	☐	☐	
Methylphenidate	Ritalin	☐	☐	☐	
Pemoline	Cylert	☐	☐	☐	
Amphetamines	Dexedrine, Desoxyn	☐	☐	☐	
Bupropion	Wellbutrin	☐	☐	☐	
Fluoxetine	Prozac	☐	☐	☐	
Sertraline	Zoloft	☐	☐	☐	
Paroxetine	Paxil	☐	☐	☐	
Fluvoxamine	Luvox	☐	☐	☐	
Amitriptyline	Elavil, Endap	☐	☐	☐	
Clomipramine	Anafranil	☐	☐	☐	
Moclobemide	Manerix	☐	☐	☐	
Lithium	Carbolith, Cibalith-S, Duralith, Eskalith, Lithane, Lithizine, Lithobid, Lithonate	☐	☐	☐	
Carbamazepine	Tegretol, Epitol	☐	☐	☐	
Valproic acid	Depakene, Depakote, Valproate	☐	☐	☐	
Gabapentin	Neurontin	☐	☐	☐	
Diazepam	Valium	☐	☐	☐	
Clonazepam	Klonopin	☐	☐	☐	
Lorazepam	Ativan, Temesta	☐	☐	☐	
Haloperidol	Haldol	☐	☐	☐	
Risperidone	Risperdal	☐	☐	☐	
Amantadine	Symmetrel	☐	☐	☐	
Acyclovir	Zovirax	☐	☐	☐	
Naltrexone	Revia	☐	☐	☐	
Flumazenil	Romazicon	☐	☐	☐	
Melatonin		☐	☐	☐	
Others (specify)					

If you were administrated several medications, please indicate which one you received first, then second, etc.

1st medication tried: ____________________________________Year___________________________

Effect on sleepiness, other symptoms, number of relapses (while on the medicine), negative effects?

2nd medication tried: ___________________________________Year________________________________

Effect

3rd medication tried: __________________________________Year________________________________

Effect

4th medication tried: __________________________________Year________________________________

Effect

If you were administrated a combination of two or more drugs together, please indicate what combination it was, and how it worked

Did you try non-medication therapy (e.g. phototherapy, diet, vitamins…)? If yes, please list, with its effects.

Were you ever treated with electroshock therapy (ECT)?

SECTION VI: Medical and laboratory Tests

Below is a list of tests that may have been performed in patients with KLS. Please check the boxes that apply to tests that you have had performed.

☐ Sleep monitoring during an episode
☐ Sleep monitoring after an episode
☐ EEG (electroencephalogram) during an episode
☐ EEG (electroencephalogram) after an episode
☐ MRI (magnetic resonance imaging)
☐ CT scan
☐ SPECT or PET (functional imaging preceded by the injection of a tracer in the blood)
☐ Lumbar puncture (spinal tap) for measures in the cerebrospinal fluid (CSF)

☐ Blood tests for measurements of hormone levels
☐ Blood tests for the presence of viruses (specify)________________________________
☐ Specific blood or antibody test for arboviruses (California encephalitis)
☐ HLA testing
☐ Other (specify) ____

Do you recall any unusual findings regarding any of these or other medical tests? Please explain

____
____
____
____
____

SECTION VII: Sleep, eating and cognitive behaviors, while not in KLS episodes

Please fill in this section that applies to your behavior while not in KLS episodes, and not immediately before or after an episode.

A - Sleep questions

1. How likely are you to doze off or fall asleep in the following situations, in contrast to feeling just tired? This refers to your usual way of life in recent times, when **not** during an episode of KLS. Even if you have not done some of these things recently, try to work out how they would have affected you. Use the following scale to choose the most appropriate number for each situation:

0= Would never doze
1= Slight chance of dozing
2= Moderate chance of dozing
3= High chance of dozing

SITUATION	CHANCE OF DOZING			
Sitting and reading	☐ 0	☐ 1	☐ 2	☐ 3
Watching TV	☐ 0	☐ 1	☐ 2	☐ 3
Sitting inactive in a public place (e.g., a theater or meeting)	☐ 0	☐ 1	☐ 2	☐ 3
As a passenger in a car for an hour without a break	☐ 0	☐ 1	☐ 2	☐ 3
Lying down to rest in the afternoon when circumstances permit	☐ 0	☐ 1	☐ 2	☐ 3
Sitting and talking to someone	☐ 0	☐ 1	☐ 2	☐ 3
Sitting quietly after a lunch without alcohol	☐ 0	☐ 1	☐ 2	☐ 3
In a car, while stopped for a few minutes in traffic	☐ 0	☐ 1	☐ 2	☐ 3

2. Do you sleep well at night, at present? YES ☐ NO ☐

3. Do you have difficulty staying awake during the day? YES ☐ NO ☐

4. What time do you usually get into bed at night? __________ am / pm

5. What time do you usually get out of bed in the morning? __________ am / pm

6. How long does it usually take you to fall asleep after the lights are off? ____ hr ____ min

7. Do you have difficulty falling asleep at night, at present YES ☐ NO ☐

8. How many times do you wake up during a typical night's sleep? _____ times. If 0 times, please go to question 11.

9. How long does your longest nighttime awakening typically last? _____ hr _____ min

10. Do you usually feel refreshed after a typical night of sleep? YES ☐ NO ☐

11. Have you ever experienced an urge to move the legs, usually accompanied or caused by uncomfortable and unpleasant sensations in the legs (restless legs)? YES ☐ NO ☐

    if no, skip to Question 15

12. Does the urge to move or do unpleasant sensations begin or worsen during periods of rest or inactivity such as lying or sitting? YES ☐ NO ☐

13. Is the urge to move or unpleasant sensations in the legs partially or totally relieved by movement, such as walking or stretching? YES ☐ NO ☐

14. Is the urge to move or unpleasant sensations worse in the evening or night than during the day or only occur in the evening or night? YES ☐ NO ☐

15. Do your legs kick during your sleep? YES ☐ NO ☐

16. Do you snore?

    Never ☐ Sometimes ☐ Frequently ☐ Almost always/always ☐

17. Has anyone ever noticed that you sometimes stop breathing during your sleep?

    YES ☐ NO ☐

18. Do you nap during the day? YES ☐ NO ☐

19. If yes, how many times per week do you take a nap? _____ times

20. How long does a typical nap last? _____ hr _____ min

21. Do you usually feel refreshed after napping? YES ☐ NO ☐

22. Do you currently experience, or have you ever experienced sleepwalking (or have your parents or bedroom partner observed you sleepwalking)?

    YES ☐ NO ☐

23. If yes, how old were you the last time you had an episode of sleepwalking? ________ years

24. Do you currently experience, or have you ever experienced night terrors (shouting with terror at night, and no dream recollection)? YES ☐ NO ☐

25. Do you currently experience, or have you ever experienced, nightmares?

    Never ☐ Rarely ☐ Quite frequently ☐ Frequently ☐

26. Do you currently experience, or have you ever experienced, episodes of muscle weakness in your legs and/or buckling of your knees during the following situations?
    - ☐ When you laugh
    - ☐ When you are surprised
    - ☐ When you tell or hear a joke
    - ☐ After athletic activities
    - ☐ When you are angry
    - ☐ I have never experienced that symptom

27. Do you currently imagine, or have you ever imagined, that you saw or heard people, animals, objects or frightening events under the following circumstances?
    - ☐ When you fall asleep abruptly
    - ☐ When you take a nap
    - ☐ When you wake up in the morning
    - ☐ When you are drowsy
    - ☐ When you wake up during the night
    - ☐ I have never experienced that symptom

28. Have you ever found yourself temporarily unable to move (paralyzed) when falling asleep or awakening?
    - ☐ When you fall asleep abruptly
    - ☐ When you take a nap
    - ☐ When you wake up in the morning
    - ☐ When you are drowsy
    - ☐ When you wake up during the night
    - ☐ I have never experienced that symptom

29. Do you have other comments or details about your sleeping habits or symptoms you would like to share for the present study?

____

____

____

B - Evaluation of mood and stress questions

Please read the sentences and check the answer that corresponds to you when <u>not in a KLS episode.</u>

1. I feel tense or "wound up."

Always ☐ A lot of the time ☐ From time to time, occasionally ☐ Not at all ☐

2. I still enjoy the things I used to enjoy.

Definitely as much ☐ Not quite as much ☐ Only a little ☐ Hardly at all ☐

3. I get a sort of frightened feeling as if something awful is about to happen.

Very definitely and quite badly ☐ Yes, but not too badly ☐
A little, but it doesn't worry me ☐ Not at all ☐

4. I can laugh and see the funny side of things.

As much as I always could ☐ Not quite so much now ☐

Definitely not so much now ☐ Not at all ☐

5. Worrying thoughts go through my mind.
A great deal of the time ☐ A lot of the time ☐
From time to time but not too often ☐ Only occasionally ☐

6.I feel cheerful.

Not at all ☐ Not often ☐ Sometimes ☐ Most of the time ☐

7. I can sit at ease and feel relaxed.

Definitely ☐ Usually ☐ Not often ☐ Not at all ☐

8. I feel as if I am slowed down.

Nearly all the time ☐ Very often ☐ Sometimes ☐ Not at all ☐

9. I get a sort of frightened feeling like "butterflies" in the stomach.

Not at all ☐ ☐ rarely Occasionally ☐ Quite often ☐ Very often ☐

10. I have lost interest in my appearance.

Definitely ☐ I don't take so much care as I should ☐
I may not take quite as much care ☐ I take just as much care as ever ☐

11. I feel restless as if I have to be on the move.

Very much indeed ☐ Quite a lot ☐ Not very much ☐ Not at all ☐

12. I look forward with enjoyment to things.

As much as I ever did ☐ Rather less than I used to ☐
Definitely less than I used to ☐ Hardly at all ☐

13. I get sudden feelings of panic.

Very often indeed ☐ Quite often ☐ Not very often ☐ Not at all ☐

14. I can enjoy a good book or radio or TV program.

Often ☐ Sometimes ☐ Not often ☐ Very seldom ☐

C - Eating attitude questions

This questionnaire assesses our behavior toward food, preferences, diet, way of eating and weight preoccupations, and possible eating disorders. Please check a response for each of the following statements (when you are not in a KLS episode):

1. Am terrified about being overweight
Always ☐ Usually ☐ Often ☐ Sometimes ☐ Rarely ☐ Never ☐

2. Avoid eating when I am hungry
Always ☐ Usually ☐ Often ☐ Sometimes ☐ Rarely ☐ Never ☐

3. Find myself preoccupied with food
Always ☐ Usually ☐ Often ☐ Sometimes ☐ Rarely ☐ Never ☐

4. Have gone on eating binges where I feel I may not be able to stop
Always ☐ Usually ☐ Often ☐ Sometimes ☐ Rarely ☐ Never ☐

5. Cut my food into small pieces
Always ☐ Usually ☐ Often ☐ Sometimes ☐ Rarely ☐ Never ☐

6. Aware of the calorie content of foods I eat
Always ☐ Usually ☐ Often ☐ Sometimes ☐ Rarely ☐ Never ☐

7. Particularly avoid food with a high carbohydrate content (bread, rice, potatoes, etc.)
Always ☐ Usually ☐ Often ☐ Sometimes ☐ Rarely ☐ Never ☐

8. Feel that others would prefer if I ate more
Always ☐ Usually ☐ Often ☐ Sometimes ☐ Rarely ☐ Never ☐

9. Vomit after I have eaten
Always ☐ Usually ☐ Often ☐ Sometimes ☐ Rarely ☐ Never ☐

10. Feel extremely guilty after eating
Always ☐ Usually ☐ Often ☐ Sometimes ☐ Rarely ☐ Never ☐

11. Am preoccupied with a desire to be thinner
Always ☐ Usually ☐ Often ☐ Sometimes ☐ Rarely ☐ Never ☐

12. Think about burning up calories when I exercise
Always ☐ Usually ☐ Often ☐ Sometimes ☐ Rarely ☐ Never ☐

13. Other people think I'm too thin
Always ☐ Usually ☐ Often ☐ Sometimes ☐ Rarely ☐ Never ☐

14. Am preoccupied with the thought of having fat on my body
Always ☐ Usually ☐ Often ☐ Sometimes ☐ Rarely ☐ Never ☐

15. Take longer than others to eat my meals
Always ☐ Usually ☐ Often ☐ Sometimes ☐ Rarely ☐ Never ☐

16. Avoid foods with sugar in them
Always ☐ Usually ☐ Often ☐ Sometimes ☐ Rarely ☐ Never ☐

17. Eat diet foods
Always ☐ Usually ☐ Often ☐ Sometimes ☐ Rarely ☐ Never ☐

18. Feel that food controls my life
Always ☐ Usually ☐ Often ☐ Sometimes ☐ Rarely ☐ Never ☐

19. Display self-control around food
Always ☐ Usually ☐ Often ☐ Sometimes ☐ Rarely ☐ Never ☐

20. Feel that others pressure me to eat
Always ☐ Usually ☐ Often ☐ Sometimes ☐ Rarely ☐ Never ☐

21. Give too much time and thought to food
Always ☐ Usually ☐ Often ☐ Sometimes ☐ Rarely ☐ Never ☐

22. Feel uncomfortable after eating sweets
Always ☐ Usually ☐ Often ☐ Sometimes ☐ Rarely ☐ Never ☐

23. Engage in dieting behavior
Always ☐ Usually ☐ Often ☐ Sometimes ☐ Rarely ☐ Never ☐

24. Like my stomach to be empty
Always ☐ Usually ☐ Often ☐ Sometimes ☐ Rarely ☐ Never ☐

25. Have the impulse to vomit after meals
Always ☐ Usually ☐ Often ☐ Sometimes ☐ Rarely ☐ Never ☐

26. Enjoy trying new rich foods
Always ☐ Usually ☐ Often ☐ Sometimes ☐ Rarely ☐ Never ☐

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Thank you very much!
Please send back this questionnaire with your blood sample. Alternatively you may send the questionnaire to :

Dr Isabelle Arnulf
Center for Narcolepsy
Stanford University School of Medicine
701-B Welch Road, Palo Alto, CA 94304 USA

Please indicate “Confidential” on the envelope.