

Questionnaire for Control or Parents of a Patient affected by Kleine-Levin Syndrome
Stanford Center for Sleep Disorder
Stanford University

CONFIDENTIAL

Foreword

Thank you for taking part, as a control, or a mother or father of a person affected by Kleine-Levin Syndrome (KLS), in our research on KLS. This questionnaire is a very important part of the research. It is a totally confidential questionnaire. Please do not skip any question.

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 Control
 Parent of a patient with Kleine-Levin syndrome
 Other Sleep Disorder Diagnosis (not Kleine-Levin syndrome) _____

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.

- | | |
|--|--|
| <input type="checkbox"/> Black _____ | <input type="checkbox"/> Native American _____ |
| <input type="checkbox"/> Pacific Islander _____ | <input type="checkbox"/> Hispanic _____ |
| <input type="checkbox"/> Caucasian (white European) _____ | <input type="checkbox"/> Asian _____ |
| <input type="checkbox"/> Jewish (specify Ashkenazi or Sephardic) _____ | <input type="checkbox"/> 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.)

- | | |
|--|--|
| <input type="checkbox"/> Black _____ | <input type="checkbox"/> Native American _____ |
| <input type="checkbox"/> Pacific Islander _____ | <input type="checkbox"/> Hispanic _____ |
| <input type="checkbox"/> Caucasian (white European) _____ | <input type="checkbox"/> Asian _____ |
| <input type="checkbox"/> Jewish (specify Ashkenazi or Sephardic) _____ | <input type="checkbox"/> 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.)

- | | |
|--|--|
| <input type="checkbox"/> Black _____ | <input type="checkbox"/> Native American _____ |
| <input type="checkbox"/> Pacific Islander _____ | <input type="checkbox"/> Hispanic _____ |
| <input type="checkbox"/> Caucasian (white European) _____ | <input type="checkbox"/> Asian _____ |
| <input type="checkbox"/> Jewish (specify Ashkenazi or Sephardic) _____ | <input type="checkbox"/> 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.)

Stanford KLS parents

- | | |
|--|--|
| <input type="checkbox"/> Black _____ | <input type="checkbox"/> Native American _____ |
| <input type="checkbox"/> Pacific Islander _____ | <input type="checkbox"/> Hispanic _____ |
| <input type="checkbox"/> Caucasian (white European) _____ | <input type="checkbox"/> Asian _____ |
| <input type="checkbox"/> Jewish (specify Ashkenazi or Sephardic) _____ | <input type="checkbox"/> 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.)

- | | |
|--|--|
| <input type="checkbox"/> Black _____ | <input type="checkbox"/> Native American _____ |
| <input type="checkbox"/> Pacific Islander _____ | <input type="checkbox"/> Hispanic _____ |
| <input type="checkbox"/> Caucasian (white European) _____ | <input type="checkbox"/> Asian _____ |
| <input type="checkbox"/> Jewish (specify Ashkenazi or Sephardic) _____ | <input type="checkbox"/> 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).

- | | |
|--|---|
| <input type="checkbox"/> Insomnia _____ | <input type="checkbox"/> Restless legs syndrome _____ |
| <input type="checkbox"/> Narcolepsy _____ | <input type="checkbox"/> Kleine-Levin syndrome _____ |
| <input type="checkbox"/> Hypersomnia _____ | <input type="checkbox"/> Sleepwalking _____ |
| <input type="checkbox"/> Sleep apnea _____ | <input type="checkbox"/> 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.

- | | |
|---|---|
| <input type="checkbox"/> Mild/moderate depression _____ | <input type="checkbox"/> Alzheimer's disease _____ |
| <input type="checkbox"/> Severe depression _____ | <input type="checkbox"/> Stroke _____ |
| <input type="checkbox"/> Suicide attempt _____ | <input type="checkbox"/> Multiple sclerosis _____ |
| <input type="checkbox"/> Parkinson's disease _____ | <input type="checkbox"/> Seizure or epilepsy _____ |
| <input type="checkbox"/> Lupus _____ | <input type="checkbox"/> Ankylosing spondylitis _____ |
| <input type="checkbox"/> Juvenile onset Type I diabetes _____ | <input type="checkbox"/> 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:

SECTION III: Personal medical history

1. Do or did you suffer from any medical problem? YES NO

Please list all your medical conditions:

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

- | | |
|--|-----------------------------------|
| <input type="checkbox"/> Abnormality at your birth | <input type="checkbox"/> Migraine |
| <input type="checkbox"/> Your birth being difficult | <input type="checkbox"/> Allergy |
| <input type="checkbox"/> Trouble in development (e.g. delayed walk, speech, reading) | <input type="checkbox"/> Seizure |
| <input type="checkbox"/> Surgery | |

Other:

3. Are you regularly taking medication? YES NO

Please detail your past and current medication, the name of the drugs you use, 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 male or female) ? _____ 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 IV: History of an Event/Party as an Adolescent:

Please answer questions in this section ONLY if you are a **control subject**. Parents of individuals with KLS need not answer questions in this section and should skip to Section V.

1. Do you remember attending your first party as an adolescent or another big event, like graduation ?
DATE ____/____/____ (month/year)

2. How old were you when it occurred? _____ years

3. In which city, state, and country were you when this event occurred?

4. Do you remember any specific events occurring before this event ?

YES NO DON'T KNOW

5. Please check any of the following if they occurred in the week before your event:

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

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

SECTION V: Sleep, eating and cognitive behaviors

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	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
Watching TV	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
Sitting inactive in a public place (e.g., a theater or meeting)	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
As a passenger in a car for an hour without a break	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
Lying down to rest in the afternoon when circumstances permit	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
Sitting and talking to someone	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
Sitting quietly after a lunch without alcohol	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
In a car, while stopped for a few minutes in traffic	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 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?

- | | |
|---|--|
| <input type="checkbox"/> When you laugh | <input type="checkbox"/> When you are surprised |
| <input type="checkbox"/> When you tell or hear a joke | <input type="checkbox"/> After athletic activities |
| <input type="checkbox"/> When you are angry | <input type="checkbox"/> 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?

- | | |
|--|--|
| <input type="checkbox"/> When you fall asleep abruptly | <input type="checkbox"/> When you take a nap |
| <input type="checkbox"/> When you wake up in the morning | <input type="checkbox"/> When you are drowsy |
| <input type="checkbox"/> When you wake up during the night | <input type="checkbox"/> I have never experienced that symptom |

28. Have you ever awakened in the morning and found you were transitory unable to move (paralyzed)?

- | | |
|--|--|
| <input type="checkbox"/> When you fall asleep abruptly | <input type="checkbox"/> When you take a nap |
| <input type="checkbox"/> When you wake up in the morning | <input type="checkbox"/> When you are drowsy |
| <input type="checkbox"/> When you wake up during the night | <input type="checkbox"/> 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 not in a KLS episode.

1. I feel tense or "wound up."

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

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

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

5. 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

6. 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

From time to time but not too often

A lot of the time

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 may not take quite as much care

I don't take so much care as I should

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

Definitely less than I used to

Rather 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 :

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

=====
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.