Sleep Disorders Research Questionnaire

-Stanford University Center for Narcolepsy and Related Disorders-

Thank you for taking the time to contribute to sleep disorders research. Please complete this questionnaire **as though you were untreated for any sleep disorder**, unless otherwise specified; in many cases, patients with sleep disorders notice a temporary increase in symptoms, known as "rebound", upon abrupt cessation of therapy. Given this possibility, **please imagine your situation either prior to treatment or after a lengthy cessation of treatment (**after the rebound has run its course). Please call 650-721-7550 if you need assistance.

SECTION I: Demographics

Date Completed: _____/_____/_____

NAME: _____
Last *First* *Middle Initial*

ADDRESS: _____
Street Address

_____
City *State* *Zip Code* *Country*

TELEPHONE: (_____)_____ (_____)_____ (_____)_____
Home *Work* *Cellular*

E-MAIL ADDRESS: _____

BIRTH DATE: _____/_____/_____ CURRENT AGE: _____
month/day/year

GENDER: □ Male □ Female

HEIGHT: _____ /_____ □ *feet/inches* □ *meter/centimeter*

WEIGHT: _____ □ *pounds* □ *kilograms*

Personal History:

Where were you born? _____
City *State/Province* *Country*

With which of the following major ethnic groups do you identify?

*Check **ALL THAT APPLY** and specify the country/countries of origin of yourself and ancestors for each group checked. For example, if you consider yourself Asian, specify whether Chinese, Korean, etc. If you consider yourself American, please specify your family's country/countries of origin prior to immigrating to the United States. If you mark other, please specify.*

□ American Indian _____ □ Asian _____
□ Black _____ □ Caucasian _____
□ Latino _____ □ Jewish □ Ashkenazi □ Sephardic □ Other
□ Pacific Islander _____ □ Other _____

Sample History (if available):

DATE OF BLOOD DRAW: _____/_____/_____ TIME OF BLOOD DRAW: _____ *am / pm*
month/day/year

DATE OF CSF DRAW: _____/_____/_____ TIME OF CSF DRAW: _____ *am / pm*
month/day/year

REASON FOR CSF DRAW: _____

SECTION II: Medical History

1. Please list all medical problems that **CURRENTLY** affect you, including narcolepsy and other sleep disorders. Please indicate whether each condition has or has not been diagnosed by a physician.

   _____

   _____

   _____

   _____

2. Please list all medications (with doses) that you are **CURRENTLY** taking, including those for narcolepsy and other sleep disorders.

   _____

   _____

   _____

   _____

3. Please list all significant medical problems that you had **IN THE PAST** (for example surgery) including narcolepsy and other sleep disorders.

   _____

   _____

   _____

   _____

Developmental History:

4. At what approximate age did you undergo puberty? _____ years
   (defined for girls as the age of their first period and for boys as the appearance of multiple pubic hairs)
5. At what approximate age do you think you reached the end of puberty? _____ years
6. At what age did you have your first menarche? *(for women only)* _____ years
7. At what age did you undergo menopause? *(for women only)* _____ years

SECTION III: Medication History

□ Not taking any medications

Medication	Duration of Treatment	Dosage range/day tried	Effect on Symptoms [increase (↑, ↑↑, ↑↑↑) no change (↔) decrease (↓, ↓↓, ↓↓↓)				
			Excessive Daytime Sleepiness	Disturbed Nocturnal Sleep	Muscle Weakness (Cataplexy) With Emotions	Hypnogogic Hallucinations When Falling Asleep	Sleep Paralysis Falling Asleep or Awakening
Sodium-Oxybate *(Xyrem)*	Day(s) □ Week(s) □ Month(s) □ Year(s) □						
NON-TRICYCLIC ANTI-CATAPLECTICS							
Citalopram *(Celexa)*	Day(s) □ Week(s) □ Month(s) □ Year(s) □						
Fluvoxamine *(Luvox)*	Day(s) □ Week(s) □ Month(s) □ Year(s) □						
Paroxetine *(Paxil)*	Day(s) □ Week(s) □ Month(s) □ Year(s) □						
Sertraline *(Zoloft)*	Day(s) □ Week(s) □ Month(s) □ Year(s) □						
Fluoxetine *(Prozac)*	Day(s) □ Week(s) □ Month(s) □ Year(s) □						
Escitalopram *(Lexapro)*	Day(s) □ Week(s) □ Month(s) □ Year(s) □						
Atomoxetine *(Strattera)*	Day(s) □ Week(s) □ Month(s) □ Year(s) □						
Venlafaxine *(Effexor)* □ Regular □ XR / SR	Day(s) □ Week(s) □ Month(s) □ Year(s) □						
TRICYCLIC ANTI-CATAPLECTICS							
Imipramine *(Janimine, Tofranil)*	Day(s) □ Week(s) □ Month(s) □ Year(s) □						
Chlomipramine *(Anafranil)*	Day(s) □ Week(s) □ Month(s) □ Year(s) □						
Protriptyline *(Vicactil)*	Day(s) □ Week(s) □ Month(s) □ Year(s) □						
Desipramine *(Desyrel)*	Day(s) □ Week(s) □ Month(s) □ Year(s) □						
STIMULANTS							
Modafinil *(Provigil)*	Day(s) □ Week(s) □ Month(s) □ Year(s) □						
Methylphenidate *(Ritalin)* □ Regular □ XR / SR	Day(s) □ Week(s) □ Month(s) □ Year(s) □						
Dextroamphetamine *(Dexedrine)* □ Regular □ XR / SR	Day(s) □ Week(s) □ Month(s) □ Year(s) □						
Methamphetamine *(Desoxyn)*	Day(s) □ Week(s) □ Month(s) □ Year(s) □						
D-L Amphetamine Salts *(Adderal)* □ Regular □ XR / SR / CD / LA	Day(s) □ Week(s) □ Month(s) □ Year(s) □						
Methylpenidate (D, L) *(Ritalin)*	Day(s) □ Week(s) □ Month(s) □ Year(s) □						
Methylphenidate (D, L) *(Concerta, Ritalin SR, Ritalin LA)*	Day(s) □ Week(s) □ Month(s) □ Year(s) □						
Demethylphenidate *(Focalin)*	Day(s) □ Week(s) □ Month(s) □ Year(s) □						
Methyphenidate Patch *(Daytrana)*	Day(s) □ Week(s) □ Month(s) □ Year(s) □						
Bupropion **(***Wellbutrin)*	Day(s) □ Week(s) □ Month(s) □ Year(s) □						
Pemoline *(Cylert)*	Day(s) □ Week(s) □ Month(s) □ Year(s) □						
SEDATIVE HYPNOTICS							
Zolpidem Tartrate *(Ambien)* □ Regular □ XR / SR	Day(s) □ Week(s) □ Month(s) □ Year(s) □						
Eszopiclone *(Lunesta)*	Day(s) □ Week(s) □ Month(s) □ Year(s) □						

Medication	Duration of Treatment	Dosage range/day tried	**Effect on Symptoms** [increase (↑, ↑↑, ↑↑↑) no change (↔) decrease (↓, ↓↓, ↓↓↓)				
			Excessive Daytime Sleepiness	Disturbed Nocturnal Sleep	Muscle Weakness (Cataplexy) With Emotions	Hypnogogic Hallucinations When Falling Asleep	Sleep Paralysis Falling Asleep or Awakening
Zaleplon *(Sonata)*	Day(s) □ Week(s) □ Month(s) □ Year(s) □						
Trazodone *(Desyrel)*	Day(s) □ Week(s) □ Month(s) □ Year(s) □						
Nefazodone *(Serzone)*	Day(s) □ Week(s) □ Month(s) □ Year(s) □						
Mirtazepine *(Remeron)*	Day(s) □ Week(s) □ Month(s) □ Year(s) □						
Other:	Day(s) □ Week(s) □ Month(s) □ Year(s) □						
Other:	Day(s) □ Week(s) □ Month(s) □ Year(s) □						
Other:	Day(s) □ Week(s) □ Month(s) □ Year(s) □						
RESTLESS LEGS SYNDROME			Leg Sensation Or Pain	Urge to Move Legs	Number of Leg Kicks At Night	Length of Time It Takes To Fall Asleep	Ability to Stay Asleep
Pramipexole *(Mirapex)*	Day(s) □ Week(s) □ Month(s) □ Year(s) □						
Ropinirole **(***Requip)*	Day(s) □ Week(s) □ Month(s) □ Year(s) □						
Carbidopa/levodopa *(Sinemet)*	Day(s) □ Week(s) □ Month(s) □ Year(s) □						
Gabapentin *(Neurontin)*	Day(s) □ Week(s) □ Month(s) □ Year(s) □						
Opoids *(list brand/type)*	Day(s) □ Week(s) □ Month(s) □ Year(s) □						
Other:	Day(s) □ Week(s) □ Month(s) □ Year(s) □						
Other:	Day(s) □ Week(s) □ Month(s) □ Year(s) □						
Other:	Day(s) □ Week(s) □ Month(s) □ Year(s) □						

8. If any of the above medications improved a symptom and you later stopped taking them, did you experience a temporary increase, or rebound, of the symptoms?

Medication _____ Symptom _____
□ Significant rebound □ Some rebound □ No rebound □ No return of symptoms

Medication _____ Symptom _____
□ Significant rebound □ Some rebound □ No rebound □ No return of symptoms

Medication _____ Symptom _____
□ Significant rebound □ Some rebound □ No rebound □ No return of symptoms

9. Do you have children? □ Yes □ No

10. a. If you have children, what was your medication regimen during pregnancy, if any *(women only)?*

_____

_____

b. If you have children, were they all born healthy? If not explain □ Yes □ No □ N/A

_____

_____

SECTION IV: Sleep History and Habits

If treated for any sleep disorder, remember to answer all questions as if you were untreated, unless specified otherwise.

Sleep Studies: *Please indicate if you had each type of sleep study and when applicable, the date and location where they were performed. If you have had multiple studies, please reference the two most recent sleep studies.*

Have you ever had a polysomnogram (sleep study with EEG)? □ **YES** □ **NO**

SLEEP CENTER #1: _____
Name of Sleep Center

ADDRESS: _____
Street Address *City* *State* *Zip Code* *Country*

TELEPHONE: (_____) _____ DATE OF STUDY: _____

PHYSICIAN'S NAME: _____ Current Physician? □ Yes □ No Prescribing Physician? □ Yes □ No

SLEEP CENTER #2: _____
Name of Sleep Center

ADDRESS: _____
Street Address *City* *State* *Zip Code* *Country*

TELEPHONE: (_____) _____ DATE OF STUDY: _____

PHYSICIAN'S NAME: _____ Current Physician? □ Yes □ No Prescribing Physician? □ Yes □ No

Have you ever had a Multiple Sleep Latency Test (MSLT, nap test)? □ **YES** □ **NO**

SLEEP CENTER #1: _____
Name of Sleep Center

ADDRESS: _____
Street Address *City* *State* *Zip Code* *Country*

TELEPHONE: (_____) _____ DATE OF STUDY: _____

PHYSICIAN'S NAME: _____ Current Physician? □ Yes □ No Prescribing Physician? □ Yes □ No

SLEEP CENTER #2: _____
Name of Sleep Center

ADDRESS: _____
Street Address *City* *State* *Zip Code* *Country*

TELEPHONE: (_____) _____ DATE OF STUDY: _____

PHYSICIAN'S NAME: _____ Current Physician? □ Yes □ No Prescribing Physician? □ Yes □ No

11. Are you a shift worker? □ Yes □ No

12. If yes, what shift do you usually work? □ Day shift □ Regular night shift □ Rotating shifts

13. At what time do you usually get into bed on a work or school night? _____AM / PM

14. At what time do you usually get out of bed on a work or school morning? _____AM / PM

15. On a work or school, how long does it take you to get out of bed? _____ hr _____ min

16. Once you are out of bed on a work or school morning, how long does it take you to feel fully awake?

_____ hr _____ min *-OR-* □ Never feel fully awake

17. At what time do you usually get into bed on a non-work or non-school night? _____AM / PM

18. a. At what time do you usually get out of bed on a non-work or non-school morning _____AM / PM

b. On a non-work or non-school, how long does it take you to get out of bed? _____ hr _____ min

19. Once you are out of bed on a non-work or non-school morning, how long does it take you to feel fully awake? _____ hr _____ min -*OR*- □ Never feel fully awake

20. How many hours of sleep do you think you need to feel fully rested? _____ hr _____ min

-*OR*- □ Never feel fully rested

21. Do you consider yourself to be a morning person ("early bird") or an evening person ("night owl")?

□ Morning person □ Evening person □ No preference

22. How strong is your morning/evening preference?

□ Strong morning preference □ Some morning preference □ Strong evening preference
□ Some evening preference □ No preference

23. Considering your preference, at what time would you ideally like to go to sleep? _____AM / PM

24. Considering your preference, at what time would you ideally like to wake up? _____AM / PM

SECTION V: Symptoms of Insomnia

For Section IV, please answer all questions unless directed to skip ahead. If you do shift work or otherwise have an unusual sleep/wake schedule, please consider "night" to be the time during which you normally sleep and "morning" to be your usual rising time. Likewise, "day" would be the period of time in which you are normally awake. If treated for any sleep disorder, remember to answer all questions as if you were untreated, unless specified otherwise.

25. In general, do you sleep well at night? □ Yes □ No

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

27. How often do you wake up too early in the morning and cannot get back to sleep?

□ Always *(every night)* □ Usually *(several times/week)* □ Often *(several times/month)*
□ Rarely *(several times/year)* □ Never

28. How often do you feel refreshed after a typical night of sleep?

□ Always *(every night)* □ Usually *(several times/week)* □ Often *(several times/month)*
□ Rarely *(several times/year)* □ Never

29. How often do you sleep restlessly?

□ Always *(every night)* □ Usually *(several times/week)* □ Often *(several times/month)*
□ Rarely *(several times/year)* □ Never

30. How often do you have difficulty falling asleep at night?

□ Always *(every night)* □ Usually *(several times/week)* □ Often *(several times/month)*
□ Rarely *(several times/year)* □ Never

31. How often do you have difficulties with maintaining sleep (waking up multiple times at night)?

□ Always *(every night)* □ Usually *(several times/week)* □ Often *(several times/month)*
□ Rarely *(several times/year)* □ Never

32. How often do you have difficulty falling asleep **and** maintaining sleep (waking up multiple times at night)?

□ Always *(every night)* □ Usually *(several times/week)* □ Often *(several times/month)*
□ Rarely *(several times/year)* □ Never

33. How often do you wake up during a **typical** night's sleep and have a difficult time falling back asleep?

_____ times

34. If you answered more than 0 times to Question 33,

    a. How long does your **typical** nighttime awakening last? _____ hr _____ min

    b. How long does your **longest** nighttime awakening last? _____ hr _____ min

    c. At what age did you **first** begin to have this problem on a regular basis? _____ years

35. If you have difficulties with sleeping well at night (insomnia), using a scale from 0 to 10 please rate how much this problem affects you (0 = no distress/impairment; 10 = severe distress/impairment):

    a. In general, how much distress does this problem cause? _____

    b. How much does it affect your social life/relationship with friends? _____

    c. How much does it affect your relationship with your spouse/family members? _____

    d. How much does it affect your relationships with your coworkers, employers teachers, or classmates? _____

SECTION VI: Symptoms of Sleepiness

If treated, remember to answer all questions as if you were untreated for any sleep disorder, unless specified otherwise.

Epworth Sleepiness Scale

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

44. How often do you have difficulty staying awake during the day?

□ Once, or more, per day □ Several times per week □ Once per week
□ Once per month □ Once per year, or less □ Never

45. How often do you experience sudden sleep attacks that are so intense that you must stop what you are doing to or take a nap?

□ Once, or more, per day □ Several times per week □ Once per week
□ Once per month □ Once per year, or less □ Never

46. a. Do you believe that you are sleepier than other individuals your age? □ Yes □ No

b. If yes, at what age did you begin to believe or become aware that you were sleepier than other individuals your age? _____ years

47. When you are very sleepy, do you ever continue your activity in a semi-automatic manner without later remembering what you have done?

□ Often □ Sometimes □ Never □ Not applicable *(never sleepy)*

48. How often do you notice making more mistakes than usual in performing an activity because of sleepiness?

□ Always *(every day)* □ Usually *(several times/week)* □ Often *(several times/month)*
□ Rarely *(several times/year)* □ Never □ Not applicable *(never sleepy)*

49. How often do you nap?

□ Multiple times a day □ Once a day □ Several times a week
□ Several times a month □ Several times a year □ Never

50. How long does a typical nap last?_____ hr _____ min □ Not applicable *(never nap)*

51. Do you typically feel refreshed after napping?

□ Always □ Sometimes □ Never □ Not applicable *(never nap)*

52. How often do you dream during your naps?

□ Always □ Sometimes □ Never □ Not applicable *(never nap)*

SECTION VII: Parasomnias

If treated, remember to answer all questions as if you were untreated for any sleep disorder, unless specified otherwise.

53. How often do you **currently** sleep walk?

□ Always *(every night)* □ Usually *(several times/week)* □ Often *(several times/month)*
□ Rarely *(several times/year)* □ Never

54. How often did you sleep walk as **a child**?

□ Always *(every night)* □ Usually *(several times/week)* □ Often *(several times/month)*
□ Rarely *(several times/year)* □ Never

55. How often do you **currently** talk in your sleep?

□ Always *(every night)* □ Usually *(several times/week)* □ Often *(several times/month)*
□ Rarely *(several times/year)* □ Never

56. How often did you sleep talk as **a child**?

□ Always *(every night)* □ Usually *(several times/week)* □ Often *(several times/month)*
□ Rarely *(several times/year)* □ Never

57. How often do act out your dreams?

□ Always *(every night)* □ Usually *(several times/week)* □ Often *(several times/month)*
□ Rarely *(several times/year)* □ Never

58. Have you ever moved so much in your sleep that you accidentally hurt yourself or your bed partner?

□ Multiple times □ Once, or a few times □ Never

SECTION VIII: Restless Legs Syndrome and Periodic Leg Movements

If treated for any sleep disorder, remember to answer all questions as if you were untreated, unless specified otherwise.

59. How often do you experienced persistent and uncomfortable feelings or sensations in your legs while sitting or lying down?

□ Always *(daily)* □ Usually *(several times/week)* □ Often *(several times/month)*
□ Rarely *(several times/year)* □ Never

60. How often do you experienced a persistent need or urge to move your legs while sitting or lying down?

□ Always *(daily)* □ Usually *(several times/week)* □ Often *(several times/month)*
□ Rarely *(several times/year)* □ Never

If do not experience either of the above symptoms as described in questions 59 and 60, please skip ahead to question 64.

61. Are these uncomfortable feelings or the urge to move your legs worse in evening or at night compared with the morning? □ Yes □ No

62. Do the uncomfortable sensations in your legs or the urge to move disappear/improve when you are active or moving around? □ Yes □ No

63. How much impact do these uncomfortable sensations have on your well-being?

□ Significant □ Moderate □ Minimal □ None

64. How often do you experience muscle twitches during your sleep or does your bed partner say that your muscles twitch?

□ Always *(every night)* □ Usually *(several times/week)* □ Often *(several times/month)*
□ Rarely *(several times/year)* □ Never

65. How often do you kick your legs during your sleep or does your bed partner say you kick your legs?

□ Always *(every night)* □ Usually *(several times/week)* □ Often *(several times/month)*
□ Rarely *(several times/year)* □ Never

SECTION IX: Sleep Disordered Breathing / Obstructive Sleep Apnea

If treated for any sleep disorder, remember to answer all questions as if you were untreated, unless specified otherwise.

66. How often do you snore or does your bed partner say that you snore? If **NEVER,** please go to question 69.

□ Always *(every night)* □ Usually *(several times/week)* □ Often *(several times/month)*
□ Rarely *(several times/year)* □ Never

67. How often, according to you or your bed partner, do you gasp, choke, make snorting sounds, or stop breathing during your sleep?

□ Always *(every night)* □ Usually *(several times/week)* □ Often *(several times/month)*
□ Rarely *(several times/year)* □ Never

68. a. Are you currently being treated for sleep apnea? □ Yes □ No

b. If yes, how is it being treated?

□ CPAP □ Oral Appliance □ Other: _____

SECTION X: Hypnogogic Hallucinations

If treated for any sleep disorder, remember to answer all questions as if you were untreated, unless specified otherwise.

69. How often do you imagine feeling/seeing/hearing unusual and/or frightening people, animals, or objects, when you…

Circumstance	Never	Rarely Only a few times ever	Infrequently Less than once/month	Sometimes At least once/month, but less than once/week	Often At least once/week
a) Fall asleep abruptly?	☐	☐	☐	☐	☐
b) Wake up in the morning?	☐	☐	☐	☐	☐
c) Take a nap?	☐	☐	☐	☐	☐
d) Are drowsy?	☐	☐	☐	☐	☐
e) Have an episode of muscle weakness?	☐	☐	☐	☐	☐
f) Wake up during the night?	☐	☐	☐	☐	☐

If you responded "Never" to **ALL** of the situations in question 69 (a-f), please skip ahead to question 76.

70. Please list below the two circumstances described in question 69 (a-f) which are most frequently associated with hallucinations and provide an explanation of each.

a. _____
Circumstance

Example: _____

_____

b. _____
Circumstance

Example: _____

_____

71. How often do you find these hallucinations frightening?

☐ Always ☐ Usually ☐ Often
☐ Rarely ☐ Never

72. How old were you the first time you experienced one of these hallucinations? _____ years

73. How long ago was your last hallucination?

☐ Within the past 24 hours ☐ Within the past week ☐ Within the past month
☐ Within the past year ☐ More than a year ago

74. If you no long experience these hallucinations, how old were you when they stopped? _____ years

75. If you no longer experience these hallucinations, please explain below why you believe they stopped *(example: medication, etc.)*

_____

_____

SECTION XI: Sleep Paralysis

If treated for any sleep disorder, remember to answer all questions as if you were untreated, unless specified otherwise.

For question 76, check the box in the column that best describes the frequency at which you experience sleep paralysis in each of the following three (a-c) situations. Please check only one box per situation.

76. How often do you…

Situation	Never	Rarely *Only a few times ever*	Infrequently *Less than once/month*	Sometimes *At least once/month, but less than once/week*	Often *At least once/week*
a) Awaken in the morning and find that you are unable to move?	☐	☐	☐	☐	☐
b) Awaken from a nap and find that you are unable to move?	☐	☐	☐	☐	☐
c) Find that you are unable to move when falling asleep, either for the night or a nap?	☐	☐	☐	☐	☐

If you responded "Never" to **ALL** of the situations in question 76 (a-c), please skip ahead to question 81.

77. If you responded yes to **ANY** of the situations described in question 76 (a-c), how old were you the first time you experienced these episodes of paralysis? _____ years

78. If you no long experience these events, how old were you when they stopped? _____ years

79. If you no longer experience these events, please explain below why you believe they stopped *(example: medication, etc.)*

_____

_____

80. When you awaken or fall asleep at night and find that you are unable to move (paralyzed) do you ever imagine unusual and/or frightening people, animals or objects? ☐ Yes ☐ No

SECTION XII: Mood

81. A number of statements which people have used to describe themselves are given below. For each item, mark the box that indicates how frequently you agree with that statement. Please check only one box per situation.

	Never	Rarely *Only a few times ever*	Infrequently *Less than once/month*	Sometimes *At least once/month, but less than once/week*	Often *At least once/week*
a) I feel pleasant	☐	☐	☐	☐	☐
b) I feel nervous and restless	☐	☐	☐	☐	☐
c) I feel satisfied with myself	☐	☐	☐	☐	☐
d) I wish I could be as happy as others seem to be	☐	☐	☐	☐	☐
e) I feel like a failure	☐	☐	☐	☐	☐
f) I feel rested	☐	☐	☐	☐	☐
g) I am "calm, cool, and collected"	☐	☐	☐	☐	☐

	Never	**Rarely** *Only a few times ever*	**Infrequently** *Less than once/month*	**Sometimes** *At least once/month, but less than once/week*	**Often** *At least once/week*
h) I feel that difficulties are piling up so that I cannot overcome them	☐	☐	☐	☐	☐
i) I worry too much about something that doesn't really matter	☐	☐	☐	☐	☐
j) I am happy	☐	☐	☐	☐	☐
k). I have disturbing thoughts	☐	☐	☐	☐	☐
l). I lack self-confidence	☐	☐	☐	☐	☐
m) I feel secure	☐	☐	☐	☐	☐
n) I make decisions easily	☐	☐	☐	☐	☐
o) I feel inadequate	☐	☐	☐	☐	☐
p) I am content	☐	☐	☐	☐	☐
q) Some unimportant thought runs through my mind and bothers me	☐	☐	☐	☐	☐
r) I take disappointments so keenly that I can't get them out of my mind	☐	☐	☐	☐	☐
s) I am a steady person	☐	☐	☐	☐	☐
t) I get in a state of tension as I think over recent concerns and interests	☐	☐	☐	☐	☐

82. Carefully read each item in the list and indicate how much you have been bothered by the symptom during the past six months, including today. Please check only one box per situation.

	Never	**Rarely** *Only a few times ever*	**Infrequently** *Less than once/month*	**Sometimes** *At least once/month, but less than once/week*	**Often** *At least once/week*
a) Numbness or tingling	☐	☐	☐	☐	☐
b) Feeling hot	☐	☐	☐	☐	☐
c) Wobbliness in legs	☐	☐	☐	☐	☐
d) Unable to relax	☐	☐	☐	☐	☐
e) Fear of the worst happening	☐	☐	☐	☐	☐
f) Dizzy or lightheaded	☐	☐	☐	☐	☐
g) Heart pounding/racing	☐	☐	☐	☐	☐
h) Unsteady	☐	☐	☐	☐	☐
i) Terrified or afraid	☐	☐	☐	☐	☐
j) Nervous	☐	☐	☐	☐	☐
k) Feeling of choking	☐	☐	☐	☐	☐
l) Hands trembling	☐	☐	☐	☐	☐
m) Shaky/Unsteady	☐	☐	☐	☐	☐
n) Fear of losing control	☐	☐	☐	☐	☐
o) Difficulty breathing	☐	☐	☐	☐	☐
p) Fear of dying	☐	☐	☐	☐	☐
q) Scared	☐	☐	☐	☐	☐
r) Indigestion	☐	☐	☐	☐	☐
s) Faint/Lightheaded	☐	☐	☐	☐	☐
t) Face flushed	☐	☐	☐	☐	☐
u) Hot/Cold sweats	☐	☐	☐	☐	☐

SECTION XIII: Muscle Weakness / Cataplexy

If treated for any sleep disorder, remember to answer all questions as if you were untreated, unless specified otherwise. For question 83 check the box that best describes the frequency at which you experience cataplexy in each of the following seven (a-g) situations. Please check only one box per situation.

83. How often do you experience episodes of muscle weakness in your legs or buckling of your knees…

	Never	**Rarely** *Only a few times ever*	**Infrequently** *Less than once/month*	**Sometimes** *At least once/month, but less than once/week*	**Often** *At least once/week*
a) When you laugh?	□	□	□	□	□
b) When you are angry?	□	□	□	□	□
c) When you tell or hear a joke?	□	□	□	□	□
d) When you are stressed?	□	□	□	□	□
e) During or after athletic activity?	□	□	□	□	□
f) Making a quick verbal response in a playful context?	□	□	□	□	□
g) During sexual intercourse?	□	□	□	□	□

If you responded "Never" to situations **a, b and c** in question 83 (a-g), you have completed the questionnaire.

84. If you experience some type of muscle weakness in association with **any** of the situations in the previous question, please indicate which muscles can be affected. If you answer "yes," to any of the symptoms below, please list the situations from question 83 (a-g) in which the type of muscle weakness occurs in **order of frequency**. For example, if you experience sagging or dropping of your jaw in association with laughter and athletic activities, please check the Yes box corresponding to sagging or dropping of your jaw and write "A, E" in the column labeled **Situation(s).**

Symptom	**Yes/No**	**Situation(s)**
a) Sagging or dropping of your jaw?	□ Yes □ No	
b) Abrupt dropping of your head and/or shoulders?	□ Yes □ No	
c) Abruptly dropped objects from your hand?	□ Yes □ No	
d) Felt weakness in your arms?	□ Yes □ No	
e) Slurring of speech?	□ Yes □ No	
f) Fallen to the ground, unable to move?	□ Yes □ No	

85. For each symptom below, please check the box corresponding to the response which best describes your **typical experience** during an episode of muscle weakness. During a typical episode of muscle weakness…

	Always	**Sometimes**	**Rarely**	**Never**	**Not Sure**
a) Can you hear?	□	□	□	□	□
b) Is your vision blurred?	□	□	□	□	□
c) Can you see?	□	□	□	□	□
d) Do you fall asleep?	□	□	□	□	□
e) In episodes in which you sleep, do you dream?	□	□	□	□	□
f) Do you have time to sit or break your fall?	□	□	□	□	□

86. How long does the muscle weakness typically last?

□ < 5 seconds □ 5– 30 seconds □ 30 seconds – 2 minutes
□ 2 – 10 minutes □ > 10 minutes

87. How frequently do you experience episodes of muscle weakness?

□ Once, or more, per day □ Several times per week □ Once per week
□ Once per month □ Once per year, or less □ Never

88. How old were you the first time that you experienced an episode of muscle weakness? _____ years

89. If you no long experience these events, how old were you when they stopped? _____ years

90. If you no longer experience these events, please explain below why you believe they stopped (example: medication, etc.)

_____

_____

Description of First Episode of Muscle Weakness:

*For questions 91-101, please complete the following questions in reference to your **FIRST** episode of muscle weakness. If you cannot remember your first episode, please select another typical instance.*

91. On what date, approximately, did your FIRST episode occur? _____
month/day/year

92. At what time of day did your FIRST episode occur?

□ Morning □ Afternoon □ Evening
□ Night □ Not sure

93. Where did it happen? *(Describe the situation – where were you and who were you with.)*

_____

_____

94. During what situation? What were you doing? *(i.e. reading, walking, meeting a friend, sitting down, watching TV, etc.)*

_____

_____

95. What, if anything, triggered it? Please describe and be specific. *(i.e. exercise, specific emotions, etc.)*

_____

_____

96. How long did the muscle weakness last?

□ A few seconds □ 1-3 minute(s) □ 3-10 minutes
□ 10-60 minutes □ More than an hour

97. Which muscles were affected? *(check all that apply)*

□ Face/Neck □ Jaw/Mouth □ Arms/Hands
□ Legs/Hips □ Whole body

98. If your arm(s) and/or leg(s) were affected, did it concern one or both sides?

□ One side □ Both sides □ Variable □ N/A

99. Were you fully awake and conscious during the episode? □ Yes □ No

100. Did you have to sit down or did you fall as a result? *(If yes, briefly describe)* □ Yes □ No

_____

_____

101. Did you attempt to fight the episode weakness*? (If yes, briefly describe)* □ Yes □ No

_____

_____

Description of Most Recent Episode:

*For questions 102-112, please complete the following questions in reference to your **MOST RECENT** episode of muscle weakness. If you cannot remember your most recent episode, please select another typical instance.*

102. On what date, approximately, did your MOST RECENT episode occur? _____
month/day/year

103. At what time of day did your MOST RECENT episode occur?

□ Morning □ Afternoon □ Evening
□ Night □ Not sure

104. Where did it happen? *(Describe the situation – where were you and who were you with.)*

_____

_____

105. During what situation? What were you doing*? (e.g. reading, walking, meeting a friend, sitting down, watching TV, etc.)*

_____

_____

106. What, if anything, triggered it? Please describe and be specific. *(i.e. exercise, specific emotions, etc.)*

_____

_____

107. How long did the muscle weakness last?

□ A few seconds □ 1-3 minutes □ 3-10 minutes
□ 10-60 minutes □ More than an hour

108. Which muscles were affected? *(check all that apply)*

□ Face/Neck □ Jaw/Mouth □ Arms/Hands
□ Legs/Hips □ Whole body

109. If your arm(s) and/or leg(s) were affected did it concern one or both sides?

□ One side □ Both sides □ Variable □ N/A

110. Were you fully awake and conscious during the episodes? □ Yes □ No

111. Did you have to sit down or did you fall as a result? *(If yes, briefly describe)* □ Yes □ No

_____

_____

112. Did you attempt to fight the episode weakness? *(If yes, briefly describe)* □ Yes □ No

_____

_____

SECTION XIV: Other Questions For Narcoleptic Patients Only

113. At what age do you think that you **definitely** had narcolepsy? _____ years

114. How abrupt was the development of your narcolepsy?

□ Days □ Weeks □ Months
□ Years □ Decades □ Not yet known

115. a. Did you gain weight around the time that you developed narcolepsy?

□ Yes □ No □ Not Sure

b. If yes, how much weight did you gain? _____ □ *pounds* □ *kilograms*

116. Which, if any, of the following conditions did you experience ONE YEAR PRIOR to the onset of narcolepsy?

Condition	**Yes/No**
a. Unexplained diarrhea	□ Yes □ No
b. Unexplained fever	□ Yes □ No
c. Cold or cold like symptoms	□ Yes □ No
d. Viral flu	□ Yes □ No
e. Strep throat	□ Yes □ No
f. Mononucleosis	□ Yes □ No
g. Herpes	□ Yes □ No
h. Food intoxication *(explain below)*	□ Yes □ No
i. Travel *(explain below)*	□ Yes □ No
j. Other *(explain below)*	□ Yes □ No

k. If you checked yes to one or more of the conditions above, please provide details in the space below *(such as the nature of head country of travel, etc.).*

_____

_____

117. How many first-degree relatives (parents, siblings, children) do you have? _____

118. How many of your first-degree relatives, if any, have narcolepsy? _____

119. How many of your first-degree relatives, if any, have narcolepsy **with** cataplexy? _____

120. a. Have you been tested for your HLA type? □ Yes □ No □ Not Sure

b. If yes, was the result indicative for narcolepsy? □ Yes □ No □ Not Sure

THANK YOU!

Please return to the following address:

Stanford University Center for Narcolepsy and Related Disorders (Attn: Mali Einen)
450 Broadway Street, M/C 5704, Redwood City, CA 94063