Affected Adults, Parents/Guardians, Legally Authorized Representatives Consent Form
Participation in Research for Affected Adults/Affected Minors
Sanford Research

Protocol Title: Coordination of Rare Diseases at Sanford (CoRDS)
Investigator: Benjamin Forred
Department: Sanford Children's Health Research Center

Instructions: If you have previously completed a CoRDS Informed Consent Form, please read carefully as the terms may have changed.

The current Informed Consent Form and Assent Form are available on the CoRDS website (http://www.sanfordresearch.org/cords/), online within the online portal, and via mail, email, or telephone per participant request. CoRDS encourages participants to review the Informed Consent Form and Assent Form regularly for any revisions. It is your responsibility to ensure you have read the current Informed Consent Form and Assent Form.

What is the purpose of this study?
The purpose of the Coordination of Rare Diseases at Sanford (CoRDS) is to establish an international rare disease patient registry. CoRDS' goal is to collect and provide a valuable resource of information, and to accelerate patient recruitment into research studies and clinical trials.

Who can participate?
Any individual with a rare, uncommon, or undiagnosed disease, as well as those who are unaffected carriers are welcome to enroll in the CoRDS Registry. A parent or guardian may enroll a child who is under the age of 18. A Legally Authorized Representative (LAR) may enroll an adult over the age of 18 who is unable to consent.

What will happen in this study?
If you choose to enroll, you will be asked to complete a brief questionnaire(s). The questionnaire(s) requests your basic contact, socio-demographic, and health information, as well as your communication and research preferences. This information will be saved under a unique coded identifier. CoRDS will send a reminder if your questionnaire has not been completed, and will send an annual reminder to update your information or confirm that it is up to date.

Is this study voluntary?
Participation in CoRDS is voluntary. You are free to withdraw at any time, for any reason. To withdraw, please contact CoRDS by mail or email and select one of the following options.

1. Leave identifiable information in CoRDS, but do not contact me again;
2. Remove identifiable information and leave de-identified information in CoRDS;
3. Remove all information from CoRDS.

You will have 30 days to decide what you wish to do with your data. CoRDS will contact you to confirm that your data has been modified/deleted according to your wishes.
If CoRDS does not hear from you within 30 days, your identifiable information will be removed and data will be stored in the registry indefinitely.

What are the benefits of this study?
There are no direct benefits to participating in CoRDS but the data you contribute may help advance research for rare diseases which would benefit a wider population. By participating in CoRDS you may be contacted about research opportunities you qualify for, and can decide at that time if you would like to participate, however CoRDS cannot guarantee that a researcher will request to contact you.

Is the information kept confidential? What are the risks of participation?
CoRDS will make every effort to keep all information gathered in the registry confidential, but this cannot be guaranteed. There is a minimal risk associated with the loss of confidentiality.

How will my information be accessed? Can I choose how my information is shared?
On the questionnaire(s), you can choose how you would like CoRDS to share your information. Information in CoRDS may be accessed in the following ways:

1. Researchers may access de-identified information if they have obtained approval from their Institutional Review Board (or equivalent approval in their country) and the CoRDS Scientific Review Committee. If you enter a disease-specific registry for a Patient Advocacy Group (PAG), that PAG may ask to be involved in the review process. If a researcher wishes to notify you about a research opportunity, CoRDS Personnel will contact you on their behalf. There is no obligation to participate – it is always up to you to contact the researcher.
2. A subset of de-identified information may be shared with certain other databases in order to avoid a duplication of efforts and to increase knowledge and understanding of rare diseases.
3. Patient Advocacy Groups (PAGs) representing individuals with rare or uncommon diseases may have access to information that may or may not be identifiable for non-research purposes. These PAGs have signed a contract stating they will not use the information for research purposes.

Who should I contact if I have questions?

- For general questions about CoRDS or enrollment: call (877) 658-9192 or email cords@sanfordhealth.org
- If you feel you have been harmed: Benjamin Forred, (605) 312-6416 If you have questions about your rights as a research participant: Sanford Health Institutional Review Board (IRB), (605) 312-6430

CoRDS Registry

Coordination of Rare Diseases at Sanford

Instructions

Thank you for taking the time to enroll with the CoRDS Registry. This questionnaire:

- Takes 10 - 20 minutes to complete
- Will refer to the person with the rare or unknown diagnosis as "**the participant**"
- Can be updated at any time by logging in to the CoRDS online portal or by contacting CoRDS personnel

CoRDS personnel will contact you annually to update your questionnaire.

If you have any questions while completing this form, please contact CoRDS at (877) 658 – 9192 during business hours, 8:30am-5:00pm (CST) Monday through Friday. If you need assistance after business hours, please leave a message or email cords@sanfordhealth.org.

*For accurate data curation, please remember to write legibly. Thank you.

1. Today's Date (MM/DD/YYYY):

2. Who is completing this questionnaire?

☐ I am enrolling myself (You must be over the age of 18 to provide information for the registry)

☐ I am enrolling my child (You must be the participant's parent or legal guardian to provide information for the registry)

☐ I am enrolling an adult who is not cognitively able to enroll (You must be the participant's legally authorized representative (LAR) to provide information for the registry)

Permissions & Data Sharing

By participating in CoRDS, your de-identified information will be shared with researchers who access the CoRDS Registry. Below are options that allow you to share your data with other entities. In the following questions, please select how you want your data shared. Please complete this section before moving on.

3. I give permission to CoRDS to contact me about participating in future research studies:

☐ Yes ☐No ☐Don't Know

4. I give permission to CoRDS to contact me about donating a sample of blood, tissue, or other biospecimen for research in the future:

☐ Yes ☐No ☐Don't Know

5. I give permission to CoRDS to provide a subset of de-identified information to other databases collecting information on rare diseases in order to avoid a duplication of efforts and to increase knowledge:

☐ Yes ☐No

Participant Information

6. First Name:	**7. Middle Name:**	**8. Last Name:**
☐ Check if the legal given name (as per birth certificate) of the participant is the same as indicated above		
Legal given name of the participant (as per birth certificate)		
9. First Name:	**10. Middle Name:**	**11. Last Name:**
12. Date of Birth:	**13. City of Birth:**	**14. Country of Birth:**
15. Address 1:		
16. Address 2:		
17. City:	**18. State**	**Province**

19. Zip/Postal Code	**20. Country**
21. Email Address:	
22. Phone Number:	

Parent / Legally Authorized Representative (LAR) Information

Please complete this section if you are the participant's parent/guardian (**participant must be under the age of 18**) or legally authorized representative (**participant is not cognitively able to enroll).**

23. First Name:		
24. Middle Name:		
25. Last Name:		
26. Primary Telephone Number:		
27. Email Address:		
☐ Check if the address is the same as the participant's, then skip to next section		
28. Address 1:		
29. Address 2:		
30. City:	**31. State**	**Province**
32. Zip/Postal Code:	**33. Country:**	

Secondary Contact

Please provide information for an individual that we may contact in the event that we are unable to reach you.

34. Relationship to Secondary Contact:

☐ Family Member ☐ Spouse/Partner

☐ Friend ☐ Other

35. If you selected "Other" above, please specify: _____

36. First Name:		
37. Middle Name:		
38. Last Name:		
39. Primary Telephone Number:		
40. Email Address:		
☐ Check if the address is the same as the participant's, then skip to next section		
41. Address 1:		
42. Address 2:		
43. City:		
44. State	**Province**	
45. Zip/Postal Code:	**46. Country:**	

Enrollment, Contact & Communication Preferences

47. How would you like to complete your annual updates?	☐Online	☐Postal mail	
48. How would you like CoRDS to contact you?	☐Email	☐Phone	☐Postal mail

49. Special Communication Needs: Do you (the person completing this form) have any special communication needs? Please select all that apply, or describe in the space provided.

☐ No special needs - both spoken and written language are acceptable
☐ Sign language required
☐ Spoken language preferred
☐ Written language preferred
☐ Other

50. If you selected "Other" above, please specify: _____

Participant Socio-demographic Information

Please provide information about the participant's background and diagnosis in the following sections.

51. Sex:	☐ Female	☐ Male	☐ Transsexual	☐ Unknown	☐ Other
52. Sex at Birth:	☐ Female	☐ Male	☐ Transsexual	☐ Unknown	☐ Other

53. Race:

☐ American Indian or Alaska Native
☐ Asian - Asian Indian
☐ Asian - Chinese
☐ Asian - Filipino
☐ Asian - Japanese
☐ Asian - Korean
☐ Asian - Vietnamese
☐ Asian - Other Asian
☐ Black or African American
☐ Pacific Islander – Native Hawaiian
☐ Pacific Islander - Guamanian
☐ Pacific Islander - Chamorro
☐ Pacific Islander- Samoan
☐ Pacific Islander - Other Pacific Islander
☐ White
☐ Other/Unknown/Refuse to Answer

54. Ethnicity:

☐ Ashkenazi Jewish
☐ French Canadian
☐ Hispanic or Latino - Central American
☐ Hispanic or Latino - Cuban
☐ Hispanic or Latino - Dominican (Republic)
☐ Hispanic or Latino - Mexican
☐ Hispanic or Latino - Puerto Rican
☐ Hispanic or Latino - South American
☐ Hispanic or Latino - Other Latin American
☐ Hispanic or Latino - Other Hispanic/Latino/Spanish
☐ Not Hispanic or Latino
☐ Unknown/No answer
☐ Other

55. If you selected "Other" above, please specify: _____

56. Is the participant still living?	☐ Yes	☐ No	☐ Don't know

57. If you selected "No" above, please indicate date of death (MM/DD/YYYY): _____

Diagnosis

58. For genetic rare diseases, is the participant an unaffected carrier of the rare disease?

☐ Yes	☐ No	☐ Unknown

59. If you selected "Yes" above, please list the rare disease for which the participant is a carrier for.

60. Rare Disease Diagnosis: Please list all rare disease diagnoses.

61. Rare Disease Symptoms: Please list symptoms of rare disease diagnoses. Separate with commas.

62. Undiagnosed: If no clinical diagnosis has been made, please list symptoms. Separate with commas.

63. Other Diagnoses: Please list non-rare diagnoses. Separate with commas.

64. Age at Diagnosis: ☐ Prenatal ☐ At birth ☐ Age ☐ Unknown ☐ N/A

65. If you selected "Age" above, please indicate age: (years and/or months) _____

66. Age at First Symptom: ☐ Prenatal ☐ At birth ☐ Age ☐ Unknown ☐ N/A

67. If you selected "Age" above, please indicate age: (years and/or months) _____

68. How was the rare diagnosis determined? Select all that apply.

☐ Genetic Laboratory Analysis
☐ Histology
☐ Imaging – CT
☐ Imaging – MRI
☐ Imaging – PET
☐ Physical Examination
☐ Unknown
☐ Other

69. If you selected "Other" above, please specify:

_____

70. Where was the diagnosis made?

Hospital / Institution: _____

City: _____

State or Province: _____

Country: _____

Family History

71. Which family members also have the participant's rare disease? Select all that apply.

☐ None
☐ Mother
☐ Father
☐ Brother
☐ Half-brother
☐ Sister
☐ Half-sister
☐ Daughter
☐ Son
☐ Maternal Grandfather
☐ Paternal Grandfather
☐ Maternal Grandmother
☐ Unknown
☐ Paternal Grandmother
☐ Maternal Aunt
☐ Paternal Aunt
☐ Maternal Uncle
☐ Paternal Uncle
☐ Maternal Cousin
☐ Paternal Cousin
☐ Granddaughter
☐ Grandson
☐ Niece
☐ Nephew

Quality of Life

72. In general, would the participant say his/her health is…

☐ Excellent	☐ Very good	☐ Good	☐Fair	☐ Poor

73. Does the participant's health now limit him/her in doing vigorous activities?

☐ Never	☐ Rarely	☐ Sometimes	☐ Often	☐ Always

74. How much did pain interfere with the participant's enjoyment of life?

☐ Never	☐ Rarely	☐ Sometimes	☐ Often	☐ Always

75. How often does the participant feel tired?

☐ Never	☐ Rarely	☐ Sometimes	☐ Often	☐ Always

76. The participant feels depressed…

☐ Never	☐ Rarely	☐ Sometimes	☐ Often	☐ Always

Clinical Research Participation & Biospecimens

77. Has the participant *previously participated in any clinical trials* related to their rare disease?

☐ Yes ☐ No ☐ Don't know

78. Does the participant *currently participate in any clinical trials* related to their rare disease?

☐ Yes ☐ No ☐ Don't know

79. Has the participant *previously donated a sample* of blood, tissue, or other biospecimen for research?

☐ Yes ☐ No ☐ Don't know

80. If Yes:

Type of biospecimen:

☐ Blood ☐ Tissue

☐ Other bodily fluid ☐ Urine

☐ Saliva/Cheek Swab ☐ Unknown

81. Location of biospecimen donation:

☐ Check here if location unknown

Hospital/ Institution:

_____

City: _____

State or Province: _____

Country:_____

Thank you for your participation!

Questions?

CoRDS Personnel

Sanford Research

2301 East 60th Street North

Sioux Falls, South Dakota 57104

Phone (toll-free)**:** 1 (877) 658-9192

Email: CoRDS@sanfordhealth.org

Instructions

Thank you for taking the time to enroll with the CoRDS/Hypersomnia Registry. This module will ask you questions specific to your diagnosis. The questions below were developed in partnership with the Hypersomnia Foundation. Please note, this module:

- Takes approximately 1 hour to complete
- Will refer to the person with the diagnosis as "**the participant**"
- References the participant's genetic report
- Can be updated at any time by logging into the CoRDS online portal or by contacting CoRDS personnel

If you have any questions while completing this form, please contact CoRDS at (877) 658-9192 during business hours, 8:30 am-5:00 pm (Central Time) Monday through Friday. If you need assistance after business hours, please leave a message or email cords@sanfordhealth.org.

Permissions & Data Sharing

I give permission to CoRDS to provide the participant's information that may or may not be identifiable to the following Patient Advocacy Group (PAG) for non-research purposes.

☐ Hypersomnia Foundation	☐ I do not give my permission

SLEEP DURATION & FREQUENCY

1. When (date OR at what age) did the participant first start feeling as if they were excessively sleepy or needed more sleep than most people?	
Date:	**Age: _____**
2. When (date OR at what age) did the participant (or their parent(s)/guardian(s)/LAR) first seek help for their excessive sleepiness or need for sleep?	
Date:	**Age:_____**
3. What is the longest the participant has ever slept at one time while TAKING MEDICATION for their excessive sleepiness or need for sleep (please round to the nearest hour)?	
_____Hours	
4. What is the longest the participant has ever slept at one time while NOT TAKING MEDICATION for their excessive sleepiness or need for sleep (please round to the nearest hour)?	

_____Hours

5. How often does the participant have difficulty waking up for the day? Please select ONE response.

- ☐ Never
- ☐ Less than once a month
- ☐ Less than once a week
- ☐ 1-2 times a week
- ☐ 3-4 times a week
- ☐ Daily or almost daily

6. How often does the participant usually feel rested after waking up for the day? Please select ONE response.

- ☐ Daily or almost daily
- ☐ 3-4 times a week
- ☐ 1-2 times a week
- ☐ 1-3 times a month
- ☐ Less than once a month
- ☐ Never

7. How long does a typical nap last for the participant (hours and/or minutes)?

Hours: _____ **Minutes: _____**

8. After a nap, how does the participant typically feel? Please select ONE response.

- ☐ Not refreshed
- ☐ Somewhat refreshed
- ☐ Refreshed

SLEEP SYMPTOMS

When answering questions 9 and 10, please think back to when the participant's symptoms WERE THE WORST they have ever been.

9. Was the participant taking medication to treat their excessive sleepiness or need for sleep when the symptoms were the worst they have ever been?

- ☐ Yes
- ☐ No

10. When the SYMPTOMS WERE THE WORST they have ever been, how often did the participant experience each of these symptoms? Please select ONLY ONE response for each row.

Symptom	Never	Once or twice in my life	Once or twice a year	Monthly	Once or twice a month	Weekly	Every day	More than once a day

Excessive daytime sleepiness								
Long sleep (sleeping longer than 10 hours at a time)								
Intentional nap (sleeping more than once in a 24-hour period)								
Fall asleep during the day without meaning to								
Use more than one alarm device to wake up								
Trouble waking up (sleep inertia) and functioning with normal alertness (sleep drunkenness)								
'Brain fog' (unable to think clearly or concentrate at any time throughout the day)								
Difficulty remembering things								
Weakness or slackness in the jaw, face, or neck with laughter or strong emotions such as anger, fear, stress, or excitement								
Sleep paralysis (being unable to move when falling asleep or waking up)								
Night sweats								
Restless sleep								
Hypersexuality								
Hyperphagia (Abnormally increased appetite and ingestion of food [typically junk food])								
Hypnagogic hallucinations (seeing or hearing things that aren't really there) when falling asleep								

Hypnopompic hallucinations (seeing or hearing things that aren't really there) when waking up								
Automatic behavior (doing something without realizing/being aware) - Automatic behavior usually happens when sleepy but trying to stay awake (e.g., arriving at a destination without being able to recall how)								

When answering questions 11 and 12, please think back over the past 30 days

11. Has the participant been taking medication (as it is normally prescribed) for their excessive sleepiness or need for sleep over the PAST 30 DAYS? Please select ONE response.

☐ Yes	☐ No	☐ No medication prescribed

12. Over the PAST 30 DAYS, how often has the participant experienced each of the following symptoms? Please select ONLY ONE response for each row.

Symptom	**Never**	**Once or twice**	**3 or 4 times**	**2-6 times each week**	**Every day**	**More than once a day**
Excessive daytime sleepiness						
Long sleep (sleeping longer than 10 hours at a time)						
Intentional nap (sleeping more than once in a 24-hour period)						
Fall asleep during the day without meaning to						
Use more than one alarm device to wake up						

Trouble waking up (sleep inertia) and functioning with normal alertness (sleep drunkenness)						
'Brain fog' (unable to think clearly or concentrate at any time throughout the day)						
Difficulty remembering things						
Weakness or slackness in the jaw, face, or neck with laughter or strong emotions such as anger, fear, stress, or excitement						
Sleep paralysis (being unable to move when falling asleep or waking up)						
Night sweats						
Restless sleep						
Hypersexuality						
Hyperphagia (Abnormally increased appetite and ingestion of food [typically junk food])						
Hypnagogic hallucinations (seeing or hearing things that aren't really there) when falling asleep						
Hypnopompic hallucinations (seeing or hearing things that aren't really there) when waking up						
Automatic behavior (doing something without realizing/being aware) - Automatic behavior usually happens when sleepy but trying to stay awake (e.g., arriving at a destination without being able to recall how)						

SLEEP SCHEDULE
Please answer the following questions as they relate to a workday (which would include paid employment, volunteer work, school, or other obligations that require the participant to be out of bed at a specific time) or non-workday (any day in which the participant does not have to be up at a specific time).
13. What time does the participant usually go to bed on workdays (ONLY SELECT either AM/PM)?
_____:_____ AM OR _____:_____ PM
14. What time does the participant usually wake up on workdays (ONLY SELECT ONE AM/PM)?

_____:_____ AM OR _____:_____ PM
15. What time does the participant usually get out of bed for their workday (ONLY SELECT ONE AM/PM)?
_____:_____ AM OR _____:_____ PM
16. How long does the participant usually sleep (NOT just lying in bed) at night on workdays?
Hours: _____ Minutes: _____
17. What time does the participant usually go to bed on non-workdays? (ONLY SELECT ONE AM/PM)
_____:_____ AM OR _____:_____ PM
18. When does the participant usually wake up on non-workdays? (ONLY SELECT ONE AM/PM)
_____:_____ AM OR _____:_____ PM
19. What time does the participant usually get out of bed for their non-workday? (ONLY SELECT ONE AM/PM)
_____:_____ AM OR _____:_____ PM
20. How long does the participant usually sleep (NOT just lying in bed) at night on non-workdays?
_____Hours & _____Minutes
21. How long does the participant usually need to sleep in order to feel rested when they wake up for the day?
☐ Not applicable – participant never feels rested
_____Hours & _____Minutes

PHYSICIAN/MEDICAL PROFESSIONALS
22. How many doctors or medical professionals has the participant seen while trying to get a diagnosis/treatment for their excessive sleepiness or need for sleep? (0-25)
_____

23. What type of doctor or medical professional diagnosed the participant's hypersomnia (gave a name to their excessive sleepiness or need for sleep)? Please select all that apply.

☐ Not applicable – participant's excessive sleepiness or need for sleep has never been diagnosed.
If not applicable, please skip to question 24.

☐ Nurse practitioner	☐ General psychiatrist
☐ Physician assistant	☐ Sleep doctor - Neurologist
☐ General internist	☐ Sleep doctor - Psychologist
☐ Family physician	☐ Sleep doctor – Psychiatrist
☐ General neurologist	☐ Sleep doctor – Pulmonary/lung specialist
☐ Pediatrician	☐ Sleep doctor – Specialty Unknown

☐ Other medical professional (please specify below)

If "Other medical professional", please specify: _____

DIAGNOSES

24. Please indicate whether any of the following disorders were a diagnosis the participant had in the past or the participant currently has and whether the participant's doctor indicated that this disease or disorder was the cause of the participant's excessive sleepiness or need for sleep.

Disease or disorder	Never been diagnosed	Diagnosed in the past, but no longer a diagnosis	Current diagnosis	Doctor said this was/is a cause of the participant's excessive sleepiness or need for sleep
Acromegaly				
Alzheimer disease				
Diabetes (type 1 or 2)				
Dysautonomia				
Hypothyroidism				

Myotonic dystrophy				
Obesity				
Parkinson disease				
Postural orthostatic tachycardia				

25. Please indicate whether any of the following disorders were a diagnosis the participant had in the past or the participant currently has and whether the participant's doctor indicated that this disease or disorder was the cause of the participant's excessive sleepiness or need for sleep.

Disease or disorder	**Never been diagnosed**	**Diagnosed in the past, but no longer a diagnosis**	**Current diagnosis**	**Doctor said this was/is a cause of the participant's excessive sleepiness or need for sleep**
Alcoholism				
Anxiety				
Attention deficit disorder (ADD)/Attention-deficit hyperactivity disorder (ADHD)				
Bipolar disorder				
Depression				
Seasonal affective disorder				
Substance abuse (including prescribed medication or other substances)				

26. Please indicate whether any of the following disorders were a diagnosis the participant had in the past or the participant currently has and whether the participant's doctor indicated that this disease or disorder was the cause of the participant's excessive sleepiness or need for sleep.

Disease or disorder	**Never been diagnosed**	**Diagnosed in the past, but no longer a diagnosis**	**Current diagnosis**	**Doctor said this was/is a cause of the paticipant's excessive sleepiness or need for sleep**
Connective tissue disorder				

Ehlers-Danlos syndrome				
Fibromyalgia				
Systemic exertion intolerance disease (also known as chronic fatigue syndrome, myalgic encephalopathy or myalgic encephalomyelitis)				

27. Please indicate whether any of these circadian rhythm disorders were a diagnosis the participant had in the past or the participant currently has and whether the participant's doctor indicated that this disease or disorder was the cause of the participant's excessive sleepiness or need for sleep.

Disease or disorder	**Never been diagnosed**	**Diagnosed in the past, but no longer a diagnosis**	**Current diagnosis**	**Doctor said this was/is a cause of the participant's excessive sleepiness or need for sleep**
Advanced sleep phase syndrome				
Delayed sleep phase syndrome				
Non-24-hour sleep-wake disorder				
Shift work sleep disorder				

28. Please indicate whether any of the following disorders were a diagnosis the participant had in the past or the participant currently has and whether the participant's doctor indicated that this disease or disorder was the cause of the participant's excessive sleepiness or need for sleep.

Disease or disorder	**Never been diagnosed**	**Diagnosed in the past, but no longer a diagnosis**	**Current diagnosis**	**Doctor said this was/is a cause of the participant's excessive sleepiness or need for sleep**
Brain tumor				
Encephalopathy				

Epilepsy or seizures				
Headaches; Chronic				
Headaches; Migraine				
Head trauma (concussion, whiplash, traumatic brain injury, loss of consciousness)				
Hydrocephalus				

29. Please indicate whether any of these hypersomnolence disorders were a diagnosis the participant had in the past or the participant currently has and whether the participant's doctor indicated that this disease or disorder was the cause of the participant's excessive sleepiness or need for sleep.

Disease or disorder	**Never been diagnosed**	**Diagnosed in the past, but no longer a diagnosis**	**Current diagnosis**	**Doctor said this was/is a cause of the participant's excessive sleepiness or need for sleep**
Hypersomnia (not otherwise specified)				
Idiopathic hypersomnia				
Kleine-Levin syndrome				
Narcolepsy; Type 1 (with cataplexy or hypocretin deficiency)				
Narcolepsy; Type 2 (without cataplexy or hypocretin deficiency)				
Narcolepsy; Type not specified				

30. Please indicate whether any of these parasomnias were a diagnosis the participant had in the past or the participant currently has and whether the participant's doctor indicated that this disease or disorder was the cause of the participant's excessive sleepiness or need for sleep.

Disease or disorder	**Never been diagnosed**	**Diagnosed in the past, but no longer a diagnosis**	**Current diagnosis**	**Doctor said this was/is a cause of the participant's excessive sleepiness or need for sleep**

Acting out dreams during sleep (REM sleep behavior disorder)				
Body rocking				
Head banging during sleep (jactatio capitis nocturna)				
Sleep talking (somniloquy)				
Sleep walking (somnambulism)				

31. Please indicate whether any of the following disorders were a diagnosis the participant had in the past or the participant currently has and whether the participant's doctor indicated that this disease or disorder was the cause of the participant's excessive sleepiness or need for sleep.

Disease or disorder	**Never been diagnosed**	**Diagnosed in the past, but no longer a diagnosis**	**Current diagnosis**	**Doctor said this was/is a cause of the participant's excessive sleepiness or need for sleep**
Insufficient sleep (that is, the participant just needs to sleep more)				
Periodic limb movements of sleep				
Restless legs syndrome				

32. Please indicate whether any of these forms of sleep apnea were a diagnosis the participant had in the past or the participant currently has and whether the participant's doctor indicated that this disease or disorder was the cause of the participant's excessive sleepiness or need for sleep.

Disease or disorder	**Never been diagnosed**	**Diagnosed in the past, but no longer a diagnosis**	**Current diagnosis**	**Doctor said this was/is a cause of the participant's excessive sleepiness or need for sleep**
Sleep apnea; Central				
Sleep apnea; Obstructive				

Sleep apnea; Mixed				
Upper airway resistance syndrome				

33. If the participant's sleepiness or excessive need for sleep began after an infection, please select the most appropriate responses below.

Infection	**Never been diagnosed**	**Diagnosed in the past, but no longer a diagnosis**	**Current diagnosis**	**Doctor said this was/is a cause of the participant's excessive sleepiness or need for sleep**
Epstein-Barr virus				
Encephalitis				
Encephalitis lethargica (sleepy sickness)				
Guillain-Barre syndrome				
H1N1/Swine flu				
HIV/AIDS				
Meningitis				
Mononucleosis or mono				
Whipple's disease				
Other infection (specify below)				

If "Other infection", please specify:

34. Please indicate whether any of these types of strokes were a diagnosis the participant had in the past or the participant currently has and whether the participant's doctor indicated that this disease or disorder was the cause of the participant's excessive sleepiness or need for sleep.

Disease or disorder	**Never been diagnosed**	**Diagnosed in the past, but no longer a diagnosis**	**Current diagnosis**	**Doctor said this was/is a cause of the participant's excessive sleepiness or need for sleep**
Stroke; Bleed (hemorrhagic)				

Stroke; Clot (thrombotic or embolic)				
Stroke; Don't know				

35. If the participant's sleepiness or excessive need for sleep began after a diagnosis that is not listed, please specify below:

36. Did the participant's excessive sleepiness or need for sleep begin shortly after receiving a vaccination?

☐ Yes	☐ No

If "Yes", please select all that apply:

☐ Human papillomavirus (HPV)	☐ Seasonal influenza (flu)
☐ Meningococcal meningitis	☐ Other vaccine (specify below)

If "Other vaccine", please specify: _____

MEDICATION

37. What stimulant medications has the participant been prescribed by a medical doctor or other medical professional for their excessive sleepiness or need for sleep? Please select ONY ONE response for each row.

Medication	Never Taken	Taken in the past, but not taking now	Currently taking at least once a week but less than every day	Currently taking every day or almost every day
Dexmethylphenidate (Focalin)				
Dextroamphetamine (Dexedrine)				
Lis-dexamfetamine (Vyvanse)				
Mazindol				

Methylphenidate (Ritalin, Metadate, Concerta, Daytrana)				
Mixed amphetamine salts (Adderall)				
Pemoline (Betanamin, Cylert, Tradon, and Ceractiv)				

If the participant's stimulant medication is not listed, please specify name(s) and whether the participant is currently taking this medication and, if so, how often:

Medication	**Never Taken**	**Taken in the past, but not taking now**	**Currently taking at least once a week but less than every day**	**Currently taking every day or almost every day**

38. What wakefulness-promoting agents has the participant been prescribed by a medical doctor or other medical professional for their excessive sleepiness or need to sleep? Please select ONLY ONE response for each row.

Wakefulness-promoting agent	**Never Taken**	**Taken in the past, but not taking now**	**Currently taking at least once a week but less than every day**	**Currently taking every day or almost every day**
Armodafinil (Nuvigi)				
Modafinil (Provigil)				

If the participant's wakefulness-promoting agent is not listed, please specify name(s) and whether the participant is currently taking this medication and, if so, how often:

Other wakefulness-promoting agent	**Taken in the past, but not taking now**	**Currently taking at least once a week but less than every day**	**Currently taking every day or almost every day**

39. What sleeping pills (sedative/hypnotics) has the participant been prescribed by a medical doctor or other medical professional for their excessive sleepiness or need to sleep? Please select ONLY ONE response for each row.

Sleeping pill (sedative/hypnotics)	Never Taken	Taken in the past, but not taking now	Currently taking at least once a week but less than every day	Currently taking every day or almost every day
Alprazolam (Xanax)				
Clonazepam (Klonopin)				
Diazepam (Valium)				
Doxepin (Silenor)				
Eszopiclone (Lunesta)				
Ramelteon (Rozerem)				
Suvorexant (Belsomra)				
Temazepam (Restoril)				
Trazodone (Desyrel, Oleptro)				
Triazolam (Halcion)				
Zaleplon (Sonata)				
Zolpidem (Ambien, Ambien CR, Intermezzon, Stilnox, Stilnoct, Sublinox, Hypnogen, Zonadin, Sanval, Zolsana)				

If the participant's sedative/hypnotic medication is not listed, please specify name(s) and whether the participant is currently taking this medication and, if so, how often:

Other Sleeping pill (sedative/hypnotics)	Taken in the past, but not taking now	Currently taking at least once a week but less than every day	Currently taking every day or almost every day

40. What antidepressant medication has a medical doctor or other medical professional ever prescribed for the participant for their excessive sleepiness or need to sleep? Please select ONLY ONE response for each row.

Antidepressant medication	Never Taken	Taken in the past, but not taking now	Currently taking at least once a week but less than every day	Currently taking every day or almost every day
Amitriptyline (Elavil)				
Bupropion (Wellbutrin)				
Citalopram (Celexa)				
Clomipramine (Anafranil)				
Duloxetine (Cymbalta)				
Escitalopram (Lexapro)				
Fluoxetine (Prozac)				
Fluvoxamine (Luvox)				
Phenelzine (Nardil)				
Protriptyline (Vivactil)				
Sertraline (Zoloft)				
Tranylcypromine (Parnate)				
Venlafaxine (Effexor)				

If the participant's antidepressant medication is not listed, please specify name(s) and whether the participant is currently taking this medication and, if so, how often:

Other Antidepressant medication	Taken in the past, but not taking now	Currently taking at least once a week but less than every day	Currently taking every day or almost every day

41. What thyroid supplements has a medical doctor or other medical professional ever prescribed for the participant for their excessive sleepiness or need to sleep? Please select ONLY ONE response for each row.

Thyroid supplement	Never Taken	Taken in the past, but not taking now	Currently taking at least once a week but less than every day	Currently taking every day or almost every day
Armour Thyroid				
Levothyroxine (Synthroid)				
Liothyronine sodium (Cytomel)				

If the participant's thyroid supplement is not listed, please specify the name(s) and whether the participant is currently taking this medication and, if so, how often:

Other Thyroid supplement	Taken in the past, but not taking now	Currently taking at least once a week but less than every day	Currently taking every day or almost every day

42. What other medications has a medical doctor or other medical professional ever prescribed for the participant for their excessive sleepiness or need to sleep?

Other medication	Never Taken	Taken in the past, but not taking now	Currently taking at least once a week but less than every day	Currently taking every day or almost every day
Atomoxetine (Strattera)				
Baclofen				
Clarithromycin (Biaxin)				
Clonidine (Catapres, Dapvay)				
Flumazenil				
Guanfacine (Intuniv, Tenex)				
Melatonin				
Sodium oxybate (Xyrem)				

If the participant's medication for their excessive sleepiness or need to sleep is not listed in any of these sections, please specify name(s) and whether the participant is currently taking this medication and, if so, how often:

Other medication	Taken in the past, but not taking now	Currently taking at least once a week but less than every day	Currently taking every day or almost every day

43. Please list all of the participant's current prescription medications (which WERE NOT USED TO TREAT THEIR EXCESSIVE DAYTIME SLEEPINESS OR NEED FOR SLEEP) and what condition the medication is used to treat.

Other medication 1:	**Condition for medication 1:**
Other medication 2:	**Condition for medication 2:**

Other medication 3:	**Condition for medication 3:**
44. What over-the counter and other non-pharmaceutical substances does the participant use to help treat their excessive sleepiness or need for sleep? Please select all that apply.	
☐ Ephedrine	☐ Caffeine
☐ Energy drinks	☐ NMDA
☐ Khat	☐ Herbal or botanical products
☐ Cocaine	☐ Methamphetamine
☐ Melatonin	☐ Other (please specify)
If "Other", please specify: _____	

Thank you for your participation!

Questions? Contact CoRDS Personnel

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