MJFF LRRK2 COHORT CONSORTIUM (LRRK2C)

1 3 5 **DEMOGRAPHICS AND PD INFORMATION** 4 0

SUBJECT ID _____ VISIT NO _____

INITIALS _____ SITE NO _____ VISIT DATE __ __ (MM) __ __ (DD) __ __ __ __ (YYYY)

DEMOGRAPHICS

1. Date of birth: 1. __ __ (MM) __ __ (DD) __ __ __ __ (YYYY)

2. Gender at birth: (1 = Female, 2 = Male) 2. ___

3a. Subject Education: (number of years) 3a. __ __

3b. Highest Level of Education: 3b. ___
1= elementary / middle school or equivalent
2 = high school or equivalent
3 = college / university or equivalent
4 = Master's level or equivalent
5 = post graduate or equivalent

4. Race:_____

5. Ethnicity:_____

NOTE: Race and Ethnicity will be captured the way each site collects this information. If you have a code and codelist, please enter the code here and provide the codelist. Otherwise, please write the race/ethnicity responses.

PD INFORMATION

6. Enrollment Category: (0 = No Parkinson disease, 1 = Parkinson disease) 6. ___

7. Age at Parkinson disease diagnosis: 7. __ __

8. Age at onset: 8. __ __

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MJFF LRRK2 COHORT CONSORTIUM (LRRK2C)

1 3 5

GENE STATUS AND FAMILY HISTORY (PD)

3 0

SUBJECT ID ☐☐☐☐☐☐☐☐☐☐☐ VISIT NO ☐☐☐

INITIALS ☐☐☐ SITE NO ☐☐☐ VISIT DATE ☐☐ ☐☐ ☐☐☐☐
MM DD YYYY

GENE STATUS

1. Is there a LRRK2 mutation in the family or does the subject carry the LRRK2 mutation? (0 = No, 1 = Yes) 1. ☐
If No (0), go to question 2
If Yes (1), indicate which one(s)

		Subject	Family
1a. G2019S	(0 = No, 1 = Yes)	1a. ☐	1a. ☐
1b. R1441G	(0 = No, 1 = Yes)	1b. ☐	1b. ☐
1c. R1441C	(0 = No, 1 = Yes)	1c. ☐	1c. ☐
1d. N1437H	(0 = No, 1 = Yes)	1d. ☐	1d. ☐
1e. G2385R	(0 = No, 1 = Yes)	1e. ☐	1e. ☐
1f. R1628P	(0 = No, 1 = Yes)	1f. ☐	1f. ☐
1g. I2020T	(0 = No, 1 = Yes)	1g. ☐	1g. ☐
1h. Q930R	(0 = No, 1 = Yes)	1h. ☐	1h. ☐
1j. S1228T	(0 = No, 1 = Yes)	1i. ☐	1i. ☐
1k. L1114L	(0 = No, 1 = Yes)	1j. ☐	1j. ☐
1l. C228S	(0 = No, 1 = Yes)	1k. ☐	1k. ☐
1m. R1325Q	(0 = No, 1 = Yes)	1l. ☐	1l. ☐
1n. Other	(0 = No, 1 = Yes)	1m. ☐	1m. ☐
		1n. ☐	1n. ☐

Specify other (subject)_____
Specify other (family)_____

FAMILY INFORMATION

2. Is the subject biologically related to someone with PD? (0 = No, 1 = Yes) 2. ☐

3. Is pedigree available at your local site? (0 = No, 1 = Yes) 3. ☐

MJFF LRRK2 COHORT CONSORTIUM (LRRK2C)

1 3 5

GENE STATUS AND FAMILY HISTORY (PD)

3 0

SUBJECT ID ☐☐☐☐☐☐☐☐☐☐☐ VISIT NO ☐☐☐

INITIALS ☐☐☐ SITE NO ☐☐☐ VISIT DATE ☐☐ ☐☐ ☐☐☐☐
MM DD YYYY

		NUMBER of FAMILY MEMBERS	NUMBER with PD or PARKINSONISM
4.	Biological Mother	4.1 1	4.2
5.	Biological Father	5.1 1	5.2
6.	Full Siblings	6.1	6.2
7.	Half Siblings	7.1	7.2
8.	Maternal Grandparents	8.1 2	8.2
9.	Paternal Grandparents	9.1 2	9.2
10.	Maternal Aunts and Uncles	10.1	11.2
11.	Paternal Aunts and Uncles	11.1	11.2
12.	Children	12.1	12.2

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MJFF LRRK2 COHORT CONSORTIUM (LRRK2C)

1 3 5 **UPDRS PART I** **[ON ONLY]** 8 A

SUBJECT ID ☐☐☐☐☐☐☐☐☐☐☐☐☐☐ VISIT NO ☐☐☐

INITIALS ☐☐☐ SITE NO ☐☐☐ VISIT DATE ☐☐ ☐☐ ☐☐☐☐
MM DD YYYY

PART I MENTATION, BEHAVIOR AND MOOD (RATE ITEMS 1 TO 4 BY INTERVIEW)
When completing this section, indicate the subject's level of function during the past week.

A. The subject's PD symptoms during the past week were: A. ☐
1 = Non Fluctuator
2 = Fluctuator

ON

1. **Intellectual Impairment:** 1.1 ☐
0 = None.
1 = Mild. Consistent forgetfulness with partial recollection of events and no other difficulties.
2 = Moderate memory loss, with disorientation and moderate difficulty handling complex problems. Mild but definite impairment of function at home with need of occasional prompting.
3 = Severe memory loss with disorientation for time and often to place. Severe impairment in handling problems.
4 = Severe memory loss with orientation preserved to person only. Unable to make judgments or solve problems. Requires much help with personal care. Cannot be left alone at all.

2. **Thought Disorder (DUE TO DEMENTIA OR DRUG INTOXICATION):** 2.1 ☐
0 = None.
1 = Vivid dreaming.
2 = "Benign" hallucinations with insight retained.
3 = Occasional to frequent hallucinations or delusions; without insight; could interfere with daily activities.
4 = Persistent hallucinations, delusions, or florid psychosis. Not able to care for self.

3. **Depression:** 3.1 ☐
0 = Not present.
1 = Periods of sadness or guilt greater than normal, never sustained for days or weeks.
2 = Sustained depression (1 week or more).
3 = Sustained depression with vegetative symptoms (insomnia, anorexia, weight loss, loss of interest).
4 = Sustained depression with vegetative symptoms and suicidal thoughts or intent.

4. **Motivation/Initiative:** 4.1 ☐
0 = Normal.
1 = Less assertive than usual; more passive.
2 = Loss of initiative or disinterest in elective (nonroutine) activities.
3 = Loss of initiative or disinterest in day-to-day (routine) activities.
4 = Withdrawn, complete loss of motivation.

MJFF LRRK2 COHORT CONSORTIUM (LRRK2C)

1 3 5 **UPDRS PART II [ON ONLY]** 1 0 A

SUBJECT ID ☐☐☐☐☐☐☐☐☐☐☐☐☐☐ VISIT NO ☐☐☐

INITIALS ☐☐☐ SITE NO ☐☐☐ VISIT DATE ☐☐ ☐☐ ☐☐☐☐
MM DD YYYY

PART II ACTIVITIES OF DAILY LIVING (RATE ITEMS 5 TO 17 BY INTERVIEW)
When completing this section, indicate the subject's level of function during the past week.

A. The subject's PD symptoms during the past week were: A. ☐
1 = Non Fluctuator
2 = Fluctuator

	ON
5. **Speech:** 0 = Normal. 1 = Mildly affected. No difficulty being understood. 2 = Moderately affected. Sometimes asked to repeat statements. 3 = Severely affected. Frequently asked to repeat statements. 4 = Unintelligible most of the time.	5.1 ☐
6. **Salivation:** 0 = Normal. 1 = Slight but definite excess of saliva in mouth; may have nighttime drooling. 2 = Moderately excessive saliva; may have minimal drooling. 3 = Marked excess of saliva with some drooling. 4 = Marked drooling, requires constant tissue or handkerchief.	6.1 ☐
7. **Swallowing:** 0 = Normal. 1 = Rare choking. 2 = Occasional choking. 3 = Requires soft food. 4 = Requires NG tube or gastrostomy feeding.	7.1 ☐
8. **Handwriting:** 0 = Normal. 1 = Slightly slow or small. 2 = Moderately slow or small; all words are legible. 3 = Severely affected; not all words are legible. 4 = The majority of words are not legible.	8.1 ☐
9. **Cutting Food and Handling Utensils:** 0 = Normal. 1 = Somewhat slow and clumsy, but no help needed. 2 = Can cut most foods, although clumsy and slow; some help needed. 3 = Food must be cut by someone, but can still feed slowly. 4 = Needs to be fed.	9.1 ☐
10. **Dressing:** 0 = Normal. 1 = Somewhat slow, but no help needed. 2 = Occasional assistance with buttoning, getting arms in sleeves. 3 = Considerable help required, but can do some things alone. 4 = Helpless.	10.1 ☐

MJFF LRRK2 COHORT CONSORTIUM (LRRK2C)

1	3	5

UPDRS PART II [ON ONLY]

1	0	A

SUBJECT ID | | | | | | | | | | | | | | VISIT NO | | | |

PART II ACTIVITIES OF DAILY LIVING

When completing this section, indicate the subject's level of function during the past week.

		ON
11.	**Hygiene:** 0 = Normal. 1 = Somewhat slow, but no help needed. 2 = Needs help to shower or bathe; or very slow in hygienic care. 3 = Requires assistance for washing, brushing teeth, combing hair, going to the bathroom. 4 = Foley catheter or other mechanical aids.	11.1 ☐
12.	**Turning in Bed and Adjusting Bedclothes:** 0 = Normal. 1 = Somewhat slow and clumsy, but no help needed. 2 = Can turn alone or adjust sheets, but with great difficulty. 3 = Can initiate, but not turn or adjust sheets alone. 4 = Helpless.	12.1 ☐
13.	**Falling (unrelated to freezing):** 0 = None. 1 = Rare falling. 2 = Occasionally falls, less than once per day. 3 = Falls an average of once daily. 4 = Falls more than once daily.	13.1 ☐
14.	**Freezing When Walking:** 0 = None. 1 = Rare freezing when walking; may have start-hesitation. 2 = Occasional freezing when walking. 3 = Frequent freezing. Occasionally falls from freezing. 4 = Frequent falls from freezing.	14.1 ☐
15.	**Walking:** 0 = Normal. 1 = Mild difficulty. May not swing arms or may tend to drag leg. 2 = Moderate difficulty, but requires little or no assistance. 3 = Severe disturbance of walking, requiring assistance. 4 = Cannot walk at all, even with assistance.	15.1 ☐
16.	**Tremor:** 0 = Absent. 1 = Slight and infrequently present. 2 = Moderate; bothersome to patient. 3 = Severe; interferes with many activities. 4 = Marked; interferes with most activities.	16.1 ☐
17.	**Sensory Complaints Related to Parkinsonism:** 0 = None. 1 = Occasionally has numbness, tingling, or mild aching. 2 = Frequently has numbness, tingling, or aching; not distressing. 3 = Frequent painful sensations. 4 = Excruciating pain.	17.1 ☐

MJFF LRRK2 COHORT CONSORTIUM (LRRK2C)

1 3 5 **UPDRS PART III** 1 2

SUBJECT ID [ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ] VISIT NO [ ][ ][ ]

INITIALS [ ][ ][ ] SITE NO [ ][ ][ ] VISIT DATE [ ][ ] [ ][ ] [ ][ ][ ][ ]
MM DD YYYY

PART III MOTOR EXAMINATION (Acceptable responses are 0, 1, 2, 3, 4)

Instructions: All efforts should be made to conduct the motor exam while the subject is in a stable state (e.g., "On" for the entire exam or "Off" for the entire exam). If unstable, re-examine the subject in a stable state if possible.

18. **Speech:** 18. [ ]
0 = Normal.
1 = Slight loss of expression, diction and/or volume.
2 = Monotone, slurred but understandable; moderately impaired.
3 = Marked impairment, difficult to understand.
4 = Unintelligible.

19. **Facial Expression:** 19. [ ]
0 = Normal.
1 = Minimal hypomimia, could be normal "Poker Face".
2 = Slight but definitely abnormal diminution of facial expression.
3 = Moderate hypomimia; lips parted some of the time.
4 = Masked or fixed facies with severe or complete loss of facial expression; lips parted 1/4 inch or more.

20. **Tremor at Rest:**
0 = Absent.
1 = Slight and infrequently present.
2 = Mild in amplitude and persistent. Or moderate in amplitude, but only intermittently present.
3 = Moderate in amplitude and present most of the time.
4 = Marked in amplitude and present most of the time.

20a. Face, lips+chin [ ]
20b. Right Hand [ ]
20c. Left Hand [ ]
20d. Right Foot [ ]
20e. Left Foot [ ]

21. **Action or Postural Tremor of Hands:**
0 = Absent.
1 = Slight; present with action.
2 = Moderate in amplitude, present with action.
3 = Moderate in amplitude with posture holding as well as action.
4 = Marked in amplitude; interferes with feeding.

21a. Right Hand [ ]
21b. Left Hand [ ]

MJFF LRRK2 COHORT CONSORTIUM (LRRK2C)

UPDRS PART III

SUBJECT ID | | | | | | | | | | | | | | VISIT NO | | | |

PART III MOTOR EXAMINATION (CONT) (Acceptable responses are 0, 1, 2, 3, 4)

22. **Rigidity:** (Judged on passive movement of major joints with subject relaxed in sitting position. Cogwheeling to be ignored.)
0 = Absent.
1 = Slight or detectable only when activated by mirror or other movements.
2 = Mild to moderate.
3 = Marked, but full range of motion easily achieved.
4 = Severe, range of motion achieved with difficulty.

22a. Neck ☐
22b. RUE ☐
22c. LUE ☐
22d. RLE ☐
22e. LLE ☐

23. **Finger Taps:** (Subject taps thumb with index finger in rapid succession with widest amplitude possible, each hand separately.)
0 = Normal.
1 = Mild slowing and/or reduction in amplitude.
2 = Moderately impaired. Definite and early fatiguing. May have occasional arrests in movement.
3 = Severely impaired. Frequent hesitation in initiating movements or arrests in ongoing movement.
4 = Can barely perform the task.

23a. Right Hand ☐
23b. Left Hand ☐

24. **Hand Movements:** (Subject opens and closes hands in rapid succession with widest amplitude possible, each hand separately.)
0 = Normal.
1 = Mild slowing and/or reduction in amplitude.
2 = Moderately impaired. Definite and early fatiguing. May have occasional arrests in movement.
3 = Severely impaired. Frequent hesitation in initiating movements or arrests in ongoing movement.
4 = Can barely perform the task.

24a. Right Hand ☐
24b. Left Hand ☐

25. **Rapid Alternating Movements of Hands:** (Pronation-supination movements of hands, vertically or horizontally, with as large an amplitude as possible, both hands simultaneously.)
0 = Normal.
1 = Mild slowing and/or reduction in amplitude.
2 = Moderately impaired. Definite and early fatiguing. May have occasional arrests in movement.
3 = Severely impaired. Frequent hesitation in initiating movements or arrests in ongoing movement.
4 = Can barely perform the task.

25a. Right Hand ☐
25b. Left Hand ☐

26. **Leg Agility:** (Subject taps heel on ground in rapid succession, picking up entire leg. Amplitude should be about 3 inches.)
0 = Normal.
1 = Mild slowing and/or reduction in amplitude.
2 = Moderately impaired. Definite and early fatiguing. May have occasional arrests in movement.
3 = Severely impaired. Frequent hesitation in initiating movements or arrests in ongoing movement.
4 = Can barely perform the task.

26a. Right Leg ☐
26b. Left Leg ☐

MJFF LRRK2 COHORT CONSORTIUM (LRRK2C)

1 3 5 **UPDRS PART III** 1 2

SUBJECT ID | | | | | | | | | | | | | | VISIT NO | | | |

PART III MOTOR EXAMINATION (CONT) (Acceptable responses are 0, 1, 2, 3, 4)

27. **Arising from Chair:** (Subject attempts to arise from a straight-back wood or metal chair with arms folded across chest.) 27. ☐
0 = Normal.
1 = Slow; or may need more than one attempt.
2 = Pushes self up from arms of seat.
3 = Tends to fall back and may have to try more than one time, but can get up without help.
4 = Unable to arise without help.

28. **Posture:** 28. ☐
0 = Normal erect.
1 = Not quite erect, slightly stooped posture; could be normal for older person.
2 = Moderately stooped posture, definitely abnormal; can be slightly leaning to one side.
3 = Severely stooped posture with kyphosis; can be moderately leaning to one side.
4 = Marked flexion with extreme abnormality of posture.

29. **Gait:** 29. ☐
0 = Normal.
1 = Walks slowly, may shuffle with short steps, but no festination or propulsion.
2 = Walks with difficulty, but requires little or no assistance; may have some festination, short steps, or propulsion.
3 = Severe disturbance of gait, requiring assistance.
4 = Cannot walk at all, even with assistance.

30. **Postural Stability:** (Response to sudden posterior displacement produced by pull on shoulders while subject is erect, with eyes open and feet slightly apart. Subject is prepared.) 30. ☐
0 = Normal.
1 = Retropulsion, but recovers unaided.
2 = Absence of postural response; would fall if not caught by examiner.
3 = Very unstable, tends to lose balance spontaneously.
4 = Unable to stand without assistance.

31. **Body Bradykinesia and Hypokinesia:** (Combining slowness, hesitancy, decreased arm swing, small amplitude, and poverty of movement in general.) 31. ☐
0 = None.
1 = Minimal slowness, giving movement a deliberate character; could be normal for some persons. Possibly reduced amplitude.
2 = Mild degree of slowness and poverty of movement which is definitely abnormal. Alternatively, some reduced amplitude.
3 = Moderate slowness, poverty or small amplitude of movement.
4 = Marked slowness, poverty or small amplitude of movement.

A. Indicate the subject's PD state during the examination: A. ☐
1 = Fluctuator - "On" during exam
2 = Fluctuator - Fluctuated during the exam
3 = Fluctuator - "Off" during exam
4 = Non-fluctuator

MJFF LRRK2 COHORT CONSORTIUM (LRRK2C)

1 3 5

UPDRS PART IV

1 4

SUBJECT ID | | | | | | | | | | | | | | VISIT NO | | | |

INITIALS | | | SITE NO | | | | VISIT DATE | | | | | | | | | | | |
MM DD YYYY

PART IV COMPLICATIONS OF THERAPY (in the past week)

A. Dyskinesias

1. **Duration:** What proportion of the waking day are dyskinesias present? (Historical information): 1. ☐
   0 = None. 3 = 51 - 75% of day.
   1 = 1 - 25% of day. 4 = 76 - 100% of day.
   2 = 26 - 50% of day.

2. **Disability:** How disabling are the dyskinesias? (Historical information; may be modified by office examination.): 2. ☐
   0 = Not disabling. 3 = Severely disabling.
   1 = Mildly disabling. 4 = Completely disabled.
   2 = Moderately disabling.

3. **Painful dyskinesias:** How painful are the dyskinesias? 3. ☐
   0 = No painful dyskinesias. 3 = Severe.
   1 = Slight. 4 = Marked.
   2 = Moderate.

4. **Presence of early morning dystonia:** (Historical information): (0 = No, 1 = Yes) 4. ☐

B. Clinical Fluctuations

5. Are any "off" periods **predictable** as to timing after a dose of medication? (0 = No, 1 = Yes) 5. ☐

6. Are any "off" periods **unpredictable** as to timing after a dose of medication? (0 = No, 1 = Yes) 6. ☐

7. Do any of the "off" periods **come on suddenly**, e.g. over a few seconds? (0 = No, 1 = Yes) 7. ☐

8. What proportion of the waking day is the subject "off" on average? 8. ☐
   0 = None. 3 = 51 - 75% of day.
   1 = 1 - 25% of day. 4 = 76 - 100% of day.
   2 = 26 - 50% of day.

C. Other Complications

9. Does the subject have anorexia, nausea, or vomiting? (0 = No, 1 = Yes) 9. ☐

10. Does the subject have any sleep disturbances, e.g., insomnia or hypersomnolence? (0 = No, 1 = Yes) 10. ☐

11. Does the subject have symptomatic orthostasis? (0 = No, 1 = Yes) 11. ☐

MJFF LRRK2 COHORT CONSORTIUM (LRRK2C)

1 3 5

MODIFIED HOEHN AND YAHR

1 6

SUBJECT ID [ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ] VISIT NO [ ][ ][ ]

INITIALS [ ][ ][ ] SITE NO [ ][ ][ ] VISIT DATE [ ][ ] [ ][ ] [ ][ ][ ][ ]
MM DD YYYY

1. Hoehn and Yahr Stage (Acceptable responses are 0, 1, 1.5, 2, 2.5, 3, 4, 5) 1. [ ] . [ ]

Stage 0 = No signs of disease.

Stage 1 = Unilateral disease.

Stage 1.5 = Unilateral plus axial involvement.

Stage 2 = Bilateral disease, without impairment of balance.

Stage 2.5 = Mild bilateral disease, with recovery on pull test.

Stage 3 = Mild to moderate bilateral disease; some postural instability; physically independent.

Stage 4 = Severe disability; still able to walk or stand unassisted

Stage 5 = Wheelchair bound or bedridden unless aided.

A. Indicate the subject's PD state during the examination: A. [ ]
1 = Fluctuator - "On" during exam
2 = Fluctuator - Fluctuated during the exam
3 = Fluctuator - "Off" during exam
4 = Non-fluctuator

MJFF LRRK2 COHORT CONSORTIUM (LRRK2C)

1 3 5

MODIFIED SCHWAB & ENGLAND ADL [ON ONLY]

1 8 A

SUBJECT ID | | | | | | | | | | | | | | VISIT NO | | |

INITIALS | | | SITE NO | | | VISIT DATE | | | | | | | | | | | |
MM DD YYYY

100% Completely independent. Able to do all chores without slowness, difficulty or impairment. Essentially normal. Unaware of any difficulty.

90% Completely independent. Able to do all chores with some degree of slowness, difficulty and impairment. Might take twice as long. Beginning to be aware of difficulty.

80% Completely independent in most chores. Takes twice as long. Conscious of difficulty and slowness.

70% Not completely independent. More difficulty with some chores. Three to four times as long in some. Must spend a large part of the day with chores.

60% Some dependency. Can do most chores, but exceedingly slowly and with much effort. Errors; some impossible.

50% More dependent. Help with half, slower, etc. Difficulty with everything.

40% Very dependent. Can assist with all chores but few alone.

30% With effort, now and then does a few chores alone or begins alone. Much help needed.

20% Nothing alone. Can be a slight help with some chores. Severe invalid.

10% Totally dependent, helpless. Complete invalid.

0% Vegetative functions such as swallowing, bladder, and bowel functions are not functioning. Bedridden.

A. The subject's PD symptoms during the past week were: A. [ ]
1 = Non Fluctuator
2 = Fluctuator

Consensus rating
(Investigator, patient, other sources)

ON
1a. | | |

Fahn S, Elton RL, Members of the UPDRS Development Committee. The Unified Parkinson's Disease Rating Scale. In Fahn S, Marsden CD, Calne DB, Goldstein M, eds. Recent developments in Parkinson's disease, vol 2. Florham Park, NJ: Macmillan Health Care Information, 1987:153-163, 293-304

MJFF LRRK2 COHORT CONSORTIUM (LRRK2C)
MONTREAL COGNITIVE ASSESSMENT (MoCA)

1 3 5 | 2 0

SUBJECT ID [ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ] VISIT NO [ ][ ][ ]

INITIALS [ ][ ][ ] SITE NO [ ][ ][ ] VISIT DATE [ ][ ] [ ][ ] [ ][ ][ ][ ]
MM DD YYYY

Record score for each item below. There is a 1 point maximum unless otherwise noted.

1. Alternating Trail Making — 1. [ ]

2. Visuoconstructional Skills (Cube) — 2. [ ]

3. Visuoconstructional Skills (Clock)
   - 3a. Contour — 3a. [ ]
   - 3b. Numbers — 3b. [ ]
   - 3c. Hands — 3c. [ ]

4. Naming
   - 4a. Lion — 4a. [ ]
   - 4b. Rhinoceros or rhino — 4b. [ ]
   - 4c. Camel or dromedary — 4c. [ ]

5. Attention
   - 5a. Forward Digit Span — 5a. [ ]
   - 5b. Backward Digit Span — 5b. [ ]
   - 5c. Vigilance — 5c. [ ]
   - 5d. Serial 7s [3 point maximum] — 5d. [ ]

6. Sentence Repetition (Language) [2 point maximum] — 6. [ ]

7. Verbal Fluency — 7. [ ]

MJFF LRRK2 COHORT CONSORTIUM (LRRK2C)
MONTREAL COGNITIVE ASSESSMENT (MoCA)

1 3 5 | 2 0

SUBJECT ID | | | | | | | | | | | | | | VISIT NO | | | |

Record score for each item below. There is a 1 point maximum unless otherwise noted.

8. Abstraction [2 point maximum] — 8. ☐

9. Delayed Recall

- 9a. Face — 9a. ☐
- 9b. Velvet — 9b. ☐
- 9c. Church — 9c. ☐
- 9d. Daisy — 9d. ☐
- 9e. Red — 9e. ☐

10. Orientation

- 10a. Date — 10a. ☐
- 10b. Month — 10b. ☐
- 10c. Year — 10c. ☐
- 10d. Day — 10d. ☐
- 10e. Place — 10e. ☐
- 10f. City — 10f. ☐

TOTAL SCORE: Sum all subscores listed (1-10f). Add 1 point for subject who has 12 years or fewer of formal education. ☐☐

SUBJECT ID ☐☐☐☐☐☐☐☐☐☐☐☐☐☐ VISIT NO ☐☐☐

INITIALS ☐☐☐ SITE NO ☐☐☐ VISIT DATE ☐☐ ☐☐ ☐☐☐☐
MM DD YYYY

A. Source of Information: 1 = Patient, 2 = Caregiver, 3 = Patient and caregiver A. ☐

SCOPA-AUT

By means of this questionnaire, we would like to find out to what extent in the past month you have had problems with various bodily functions, such as difficulty passing urine, or excessive sweating. Answer the questions by placing a cross in the box which best reflects your situation. If you wish to change an answer, fill in the 'wrong' box and place a cross in the correct one. If you have used medication in the past month in relation to one or more of the problems mentioned, then the question refers to how you were while taking this medication. You can note the use of medication on the last page.

1. In the past month have you had difficulty swallowing or have you choked?

☐ never ☐ sometimes ☐ regularly ☐ often

2. In the past month, has saliva dribbled out of your mouth?

☐ never ☐ sometimes ☐ regularly ☐ often

3. In the past month, has food ever become stuck in your throat?

☐ never ☐ sometimes ☐ regularly ☐ often

4. In the past month, did you ever have the feeling during a meal that you were full very quickly?

☐ never ☐ sometimes ☐ regularly ☐ often

5. *Constipation is a blockage of the bowel, a condition in which someone has a bowel movement twice a week or less.*
In the past month, have you had problems with constipation?

☐ never ☐ sometimes ☐ regularly ☐ often

6. In the past month, did you have to strain hard to pass stools?

☐ never ☐ sometimes ☐ regularly ☐ often

SUBJECT ID | | | | | | | | | | | | | | VISIT NO | | | |

7. In the past month, have you had involuntary loss of stools?

☐ never ☐ sometimes ☐ regularly ☐ often

Questions 8 to 13 deal with problems with passing urine. If you use a catheter you can indicate this by placing a cross in the box *"use catheter"*.

8. In the past month, have you had difficulty retaining urine?

☐ never ☐ sometimes ☐ regularly ☐ often ☐ *use catheter*

9. In the past month, have you had involuntary loss of urine?

☐ never ☐ sometimes ☐ regularly ☐ often ☐ *use catheter*

10. In the past month, have you had the feeling that after passing urine your bladder was not completely empty?

☐ never ☐ sometimes ☐ regularly ☐ often ☐ *use catheter*

11. In the past month, has the stream of urine been weak?

☐ never ☐ sometimes ☐ regularly ☐ often ☐ *use catheter*

12. In the past month, have you had to pass urine again within 2 hours of the previous time?

☐ never ☐ sometimes ☐ regularly ☐ often ☐ *use catheter*

13. In the past month, have you had to pass urine <u>at night</u>?

☐ never ☐ sometimes ☐ regularly ☐ often ☐ *use catheter*

SUBJECT ID | | | | | | | | | | | | | | VISIT NO | | | |

14. In the past month, when standing up have you had the feeling of either becoming light-headed, or no longer being able to see properly, or no longer being able to think clearly?

☐ never ☐ sometimes ☐ regularly ☐ often

15. In the past month, did you become light-headed after standing for some time?

☐ never ☐ sometimes ☐ regularly ☐ often

16. Have you fainted in the past 6 months?

☐ never ☐ sometimes ☐ regularly ☐ often

17. In the past month, have you ever perspired excessively during the day?

☐ never ☐ sometimes ☐ regularly ☐ often

18. In the past month, have you ever perspired excessively during the night?

☐ never ☐ sometimes ☐ regularly ☐ often

19. In the past month, have your eyes ever been over-sensitive to bright light?

☐ never ☐ sometimes ☐ regularly ☐ often

20. In the past month, how often have you had trouble tolerating cold?

☐ never ☐ sometimes ☐ regularly ☐ often

21. In the past month, how often have you had trouble tolerating heat?

☐ never ☐ sometimes ☐ regularly ☐ often

SUBJECT ID | | | | | | | | | | | | | | VISIT NO | | | |

The following questions are about sexuality. Although we are aware that sexuality is a highly intimate subject, we would still like you to answer these questions. For the questions on sexual activity, consider every form of sexual contact with a partner or masturbation (self-gratification). An extra response option has been added to these questions. Here you can indicate that the situation described has not been applicable to you in the past month, for example because you have not been sexually active. Questions 22 and 23 are intended specifically for men, 24 and 25 for women.

The following 3 questions are only for men

22. In the past month, have you been impotent (unable to have or maintain an erection)?

☐ never ☐ sometimes ☐ regularly ☐ often ☐ *not applicable*

23. In the past month, how often have you been unable to ejaculate?

☐ never ☐ sometimes ☐ regularly ☐ often ☐ *not applicable*

23a. In the past month, have you taken medication for an erection disorder? (If so, which medication?)

☐ no ☐ yes: _____

Proceed with question 26

The following 2 questions are only for women

24. In the past month, was your vagina too dry during sexual activity?

☐ never ☐ sometimes ☐ regularly ☐ often ☐ *not applicable*

25. In the past month, have you had difficulty reaching an orgasm?

☐ never ☐ sometimes ☐ regularly ☐ often ☐ *not applicable*

SUBJECT ID | | | | | | | | | | | | | | VISIT NO | | | |

The following questions are for everyone

26. In the past month, have you used medication for:

a. constipation? ☐ no ☐ yes: _____

b. urinary problems? ☐ no ☐ yes: _____

c. blood pressure? ☐ no ☐ yes: _____

d. other symptoms *(not symptoms related to Parkinson's disease)* ☐ no ☐ yes: _____

_____

© This questionnaire is made available free of charge, with the permission of the authors, to all those undertaking non-profit and profit making research. Future users may be requested to share data for psychometric purposes. Use of this questionnaire in studies should be communicated to the developers. No changes may be made to the questionnaire without written permission. Please use the following reference in publications:

Visser M, Marinus J, Stiggelbout AM, van Hilten JJ. Assessment of autonomic dysfunction in Parkinson's disease: The SCOPA-AUT. Mov Disord. 2004;19:1306-12.

For further information, please contact M.Visser, Leiden University Medical Center, Department of Neurology (K5Q), P.O. Box 9600, NL-2300 RC Leiden (email: m.visser@lumc.nl).

MJFF LRRK2 COHORT CONSORTIUM (LRRK2C)
GERIATRIC DEPRESSION SCALE (Short Version)

1 3 5 | 2 4

SUBJECT ID | VISIT NO

INITIALS | SITE NO | VISIT DATE MM DD YYYY

Choose the best answer for how you have felt over the **past week**. (0 = No, 1 = Yes)

1. Are you basically satisfied with your life? 1. ☐
2. Have you dropped many of your activities and interests? 2. ☐
3. Do you feel that your life is empty? 3. ☐
4. Do you often get bored? 4. ☐
5. Are you in good spirits most of the time? 5. ☐
6. Are you afraid that something bad is going to happen to you? 6. ☐
7. Do you feel happy most of the time? 7. ☐
8. Do you often feel helpless? 8. ☐
9. Do you prefer to stay at home, rather than going out and doing new things? 9. ☐
10. Do you feel you have more problems with memory than most? 10. ☐
11. Do you think it is wonderful to be alive now? 11. ☐
12. Do you feel pretty worthless the way you are now? 12. ☐
13. Do you feel full of energy? 13. ☐
14. Do you feel that your situation is hopeless? 14. ☐
15. Do you think that most people are better off than you are? 15. ☐

Sheikh JI, Yesavage JA: Geriatric Depression Scale (GDS): Recent evidence and development of a shorter version. Clinical Gerontology: A Guide to Assessment and Intervention. 165-173, NY: The Haworth Press, 1986.

MJFF LRRK2 COHORT CONSORTIUM (LRRK2C)

1 3 5

EPWORTH SLEEPINESS SCALE

2 8

SUBJECT ID | | | | | | | | | | | | | | VISIT NO | | | |

INITIALS | | | | SITE NO | | | | VISIT DATE | | | | | | | | | | | |
MM DD YYYY

A. Source of Information: 1 = Patient, 2 = Caregiver, 3 = Patient and caregiver A. ☐

How likely are you to doze off or fall asleep in situations described below, in contrast to feeling just tired?

This refers to your usual way of life in recent times.

Even if you haven't 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

It is important that you answer each question as best you can.

1. Sitting and reading 1. ☐
2. Watching TV 2. ☐
3. Sitting, inactive in a public place (e.g., a theatre or a meeting) 3. ☐
4. As a passenger in a car for an hour without a break 4. ☐
5. Lying down to rest in the afternoon when circumstances permit 5. ☐
6. Sitting and talking to someone 6. ☐
7. Sitting quietly after a lunch without alcohol 7. ☐
8. In a car, while stopped for a few minutes in the traffic 8. ☐

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MJFF LRRK2 COHORT CONSORTIUM (LRRK2C)

1 3 5

REM SLEEP DISORDER QUESTIONNAIRE

3 8

SUBJECT ID ☐☐☐☐☐☐☐☐☐☐☐☐☐☐ VISIT NO ☐☐☐

INITIALS ☐☐☐ SITE NO ☐☐☐ VISIT DATE ☐☐ ☐☐ ☐☐☐☐
MM DD YYYY

A. Source of Information: 1 = Patient, 2 = Caregiver, 3 = Patient and caregiver A. ☐

1. I sometimes have very vivid dreams. (0 = No, 1 = Yes) 1. ☐

2. My dreams frequently have an aggressive or action-packed content. (0 = No, 1 = Yes) 2. ☐

3. The dream contents mostly match my nocturnal behaviour. (0 = No, 1 = Yes) 3. ☐

4. I know that my arms or legs move when I sleep. (0 = No, 1 = Yes) 4. ☐

5. It thereby happened that I (almost) hurt my bed partner or myself. (0 = No, 1 = Yes) 5. ☐

6. I have or had the following phenomena during my dreams:

   6.1 speaking, shouting, swearing, laughing loudly (0 = No, 1 = Yes) 6.1 ☐

   6.2 sudden limb movements, “fights” (0 = No, 1 = Yes) 6.2 ☐

   6.3 gestures, complex movements, that are useless during sleep, e.g., to wave, to salute, to frighten mosquitoes, falls off the bed (0 = No, 1 = Yes) 6.3 ☐

   6.4 things that fell down around the bed, e.g., bedside lamp, book, glasses (0 = No, 1 = Yes) 6.4 ☐

7. It happens that my movements awake me. (0 = No, 1 = Yes) 7. ☐

8. After awakening I mostly remember the content of my dreams well. (0 = No, 1 = Yes) 8. ☐

9. My sleep is frequently disturbed. (0 = No, 1 = Yes) 9. ☐

1 3 5

REM SLEEP DISORDER QUESTIONNAIRE

3 8

SUBJECT ID | | | | | | | | | | | | | | VISIT NO | | | |

10. I have/had a disease of the nervous system: (0 = No, 1 = Yes)

10a. stroke 10a. ☐

10b. head trauma 10b. ☐

10c. parkinsonism 10c. ☐

10d. RLS 10d. ☐

10e. narcolepsy 10e. ☐

10f. depression 10f. ☐

10g. epilepsy 10g. ☐

10h. inflammatory disease of the brain 10h. ☐

10i. other, specify: _____ 10i. ☐

MJFF LRRK2 COHORT CONSORTIUM (LRRK2C)

1 3 5

UNIVERSITY OF PENNSYLVANIA SMELL ID TEST

4 2

SUBJECT ID | | | | | | | | | | | VISIT NO | | | |

INITIALS | | | SITE NO | | | | VISIT DATE | | | | | | | | | | | |
MM DD YYYY

Record score from each booklet.

1. Score from booklet #1: 1. | |

2. Score from booklet #2: 2. | |

3. Score from booklet #3: 3. | |

4. Score from booklet #4: 4. | |

5. Comments:

_____

_____

_____

MJFF LRRK2 COHORT CONSORTIUM (LRRK2C)

1 3 5 **IMAGING AND ADDITIONAL MEASURES** 4 4

SUBJECT ID _____ VISIT NO _____

INITIALS _____ SITE NO _____ VISIT DATE __ __ (MM) __ __ (DD) __ __ __ __ (YYYY)

Please indicate which measures were performed. This may be be the source of data for additional research questions.

IMAGING

1. DatSCAN completed? (0 = No, 1 = Yes) 1. ☐

   1a. If Yes (1), date DatSCAN completed: 1a. __ __ (MM) __ __ (DD) __ __ __ __ (YYYY)

2. MRI scan completed? (0 = No, 1 = Yes) 2. ☐

   2a. If Yes (1), date MRI scan completed: 2a. __ __ (MM) __ __ (DD) __ __ __ __ (YYYY)

3. FDG PET completed? (0 = No, 1 = Yes) 3. ☐

   3a. If Yes (1), date FDG PET completed: 3a. __ __ (MM) __ __ (DD) __ __ __ __ (YYYY)

4. Transcranial ultrasound completed? (0 = No, 1 = Yes) 4. ☐

   4a. If Yes (1), date transcranial ultrasound completed: 4a. __ __ (MM) __ __ (DD) __ __ __ __ (YYYY)

ADDITIONAL MEASURES

5. Post Mortem Brain collected? (0 = No, 1 = Yes) 5. ☐

6. DNA collected? (0 = No, 1 = Yes) 6. ☐

7. Lymphocytes collected? (0 = No, 1 = Yes) 7. ☐

8. Skin fibroblasts collected? (0 = No, 1 = Yes) 8. ☐

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MJFF LRRK2 COHORT CONSORTIUM (LRRK2C)
DIAGNOSTIC CHECK SHEET

1 3 5 | 4 6

SUBJECT ID [ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ] VISIT NO [ ][ ][ ]

INITIALS [ ][ ][ ] SITE NO [ ][ ][ ] VISIT DATE [ ][ ] [ ][ ] [ ][ ][ ][ ]
MM DD YYYY

Directions for items 1 - 22b: Does the subject have a **history** of or **present at this visit** with the following signs or symptoms? (0 = No, 1 = Yes)

1. Bradykinesia 1. [ ]

2. Rigidity 2. [ ]

3a. Resting tremor 3a. [ ]

3b. If resting tremor, is it 4-6 Hz? (0 = No, 1 = Yes, 2 = Not applicable) 3b. [ ]

4a. Asymmetric onset 4a. [ ]

4b. If asymmetric, was it unilateral onset? (0 = No, 1 = Yes, 2 = Not applicable) 4b. [ ]

5. Persistent asymmetry affecting the side of onset most 5. [ ]

6. Progressive disorder 6. [ ]

7. Sustained remission 7. [ ]

8. History of repeated strokes with stepwise progression of Parkinsonian features 8. [ ]

9. History of repeated head injury 9. [ ]

10. History of definite encephalitis 10. [ ]

11. Oculogyric crisis 11. [ ]

12. Presence of a cerebral tumour or communicating hydrocephalus on CT scan 12. [ ]

13. MPTP exposure 13. [ ]

14. Severe levodopa-induced chorea 14. [ ]

MJFF LRRK2 COHORT CONSORTIUM (LRRK2C)
DIAGNOSTIC CHECK SHEET

SUBJECT ID | | | | | | | | | | | | | | VISIT NO | | | |

Directions for items 1 - 22b (continued) : Does the subject have a **history** of or **present at this visit** with the following signs or symptoms? (0 = No, 1 = Yes)

15. Cerebellar signs — 15. ☐

16. Babinski sign — 16. ☐

17. Supranuclear gaze palsy (other than restriction of upward gaze) or slowing of vertical saccades — 17. ☐

18. More than one affected relative — 18. ☐

19a. Does the subject have documentation of a condition known to produce parkinsonism and plausibly connected to the subject's symptoms (such as suitably located focal brain lesions or neuroleptic use within the past 6 months)? — 19a. ☐

19b. Did the subject have neuroleptic treatment at onset of symptoms? — 19b. ☐

20a. Does the subject have a history of or present at this visit with severe symptomatic dysautonomia unrelated to medications? — 20a. ☐

20b. If the subject has experienced severe autonomic involvement was it early in disease? (0 = No, 1 = Yes, 2 = Not applicable) — 20b. ☐

21a. Did the subject experience dementia preceding motor symptoms or in the first year? — 21a. ☐

21b. If the subject has experienced early severe dementia, did it also include disturbance of memory, language and praxis? (0 = No, 1 = Yes, 2 = Not applicable) — 21b. ☐

22a. Does the subject have a history of or present at this visit with postural instability not caused by primary visual, vestibular, cerebellar or proprioceptive dysfunction? — 22a. ☐

22b. If subject experienced prominent postural instability did it occur in the first 3 years after symptom onset? (0 = No, 1 = Yes, 2 = Not applicable) — 22b. ☐

MJFF LRRK2 COHORT CONSORTIUM (LRRK2C)
DIAGNOSTIC CHECK SHEET

1 3 5 | 4 6

SUBJECT ID | | | | | | | | | | | | | | VISIT NO | | | |

Directions for items 23 - 26: Does the subject have a **history** of following? (0 = No, 1 = Yes)

23. Freezing phenomena in the first 3 years — 23. ☐

24. Hallucinations unrelated to medications in the first 3 years — 24. ☐

25. Strictly unilateral features after 3 years — 25. ☐

26. Clinical course of 10 years or more — 26. ☐

27. Levodopa response: — 27. ☐
    1 = Subject has not had an adequate trial of levodopa or dopamine agonist
    2 = Substantial and sustained response to levodopa or a dopamine agonist
    3 = Negative response to large dose of levodopa (if malabsorption excluded)
    4 = Response to levodopa or a dopamine agonist, but either not substantial or not sustained

28. In your opinion, what is this subject's response to levodopa? — 28. ☐
    1 = 70% - 100% reduction in PD signs and symptoms
    2 = 50% - 69% reduction in PD signs and symptoms
    3 = 1% - 49% reduction in PD signs and symptoms
    4 = no (0%) reduction in PD signs and symptoms
    5 = has never had an adequate trial of levodopa

29. If responsive to levodopa, has the response been present for 5 years or more? (0 = No, 1 = Yes) — 29. ☐

30. In your opinion, what is the probability that this individual has Parkinson's disease? — 30. ☐
    1 = 90% - 100%
    2 = 50% - 89%
    3 = 10% - 49%
    4 = 0% - 9%

SUBJECT ID |__|__|__|__|__|__|__|__|__|__|__|__|__|__| VISIT NO |__|__|__|

INITIALS |__|__|__| SITE NO |__|__|__| VISIT DATE |__|__| |__|__| |__|__|__|__|
MM DD YYYY

PD RFQ-U - CAFFEINE

The following questions ask about your use of caffeine throughout your lifetime. Please answer these questions to the best of your ability.

SECTION A: CAFFEINATED COFFEE

A1) In your lifetime, have you ever regularly drunk caffeinated coffee, that is, at least once per week for 6 months or longer?

1 ☐ Yes → GO TO A2

0 ☐ No → **(SKIP TO SECTION B)**

-9 ☐ Don't Know → **(SKIP TO SECTION B)**

-7 ☐ Refused → **(SKIP TO SECTION B)**

A2) At what age (or in what year) did you start regularly drinking caffeinated coffee?

	Age started		Year started	Don't know	Refused
Caffeinated Coffee	|__|__|	or	|__|__|__|__|	-9 ☐	-7 ☐

A3) At what age (or in what year) did you stop regularly drinking caffeinated coffee?

	Age stopped		Year stopped	Currently drink	Don't know	Refused
Caffeinated Coffee	|__|__|	or	|__|__|__|__|	-5 ☐	-9 ☐	-7 ☐

SUBJECT ID | | | | | | | | | | | | | | VISIT NO | | |

A4) During this time, were there periods totaling 5 or more years when you did NOT regularly drink caffeinated coffee?

1 ☐ Yes

→ A4a) During this time, approximately how many years in total did you NOT regularly drink caffeinated coffee: _____ **yrs**

→ A4b) What ages were you when you did NOT regularly drink caffeinated coffee? (If there were multiple periods when you did not regularly drink, please report each period separately.)

AGE: |__|__| **to** AGE: |__|__|
AGE: |__|__| **to** AGE: |__|__|
AGE: |__|__| **to** AGE: |__|__|

0 ☐ No
-9 ☐ Don't Know
-7 ☐ Refused

A5) Averaging over your lifetime, during the time you were regularly drinking caffeinated coffee, about <u>how many cups per week</u> did you drink?

Number		of cups/week	Don't know	Refused
Caffeinated	Coffee	|__|__|	-9 ☐	-7 ☐

SECTION B: CAFFEINATED BLACK TEA

B1) In your lifetime, have you ever regularly drunk hot or iced caffeinated black tea, that is, at least once per week for 6 months or longer? (black tea includes most types of non-herbal tea, such as Lipton, Earl Grey and others)

1 ☐ Yes → GO TO B2

0 ☐ No → **(SKIP TO SECTION C)**

-9 ☐ Don't Know → **(SKIP TO SECTION C)**

-7 ☐ Refused → **(SKIP TO SECTION C)**

B2) At what age (or in what year) did you <u>start</u> regularly drinking caffeinated black tea?

	Age started		Year started	Don't know	Refused
Caffeinated black tea	|__|__|	or	|__|__|__|__|	-9 ☐	-7 ☐

B3) At what age (or in what year) did you <u>stop</u> regularly drinking caffeinated black tea?

	Age stopped		Year stopped	Currently drink	Don't know	Refused
Caffeinated black tea	|__|__|	or	|__|__|__|__|	-5 ☐	-9 ☐	-7 ☐

B4) During this time, were there periods totaling 5 or more years when you did NOT regularly drink caffeinated black tea?

1 ☐ Yes

→ B4a) During this time, approximately how many years in total did you NOT regularly drink caffeinated black tea: _____ **yrs**

→ B4b) What ages were you when you did NOT regularly drink caffeinated black tea? (If there were multiple periods when you did not regularly drink, please report each period separately.)

AGE: |__|__| **to** AGE: |__|__|
→ AGE: |__|__| **to** AGE: |__|__|
AGE: |__|__| **to** AGE: |__|__|

0 ☐ No
-9 ☐ Don't Know
-7 ☐ Refused

B5) Averaging over your lifetime, during the time you were regularly drinking caffeinated black tea, about <u>how many cups per week</u> did you drink?

Number of	cups/week	Don't know	Refused
Caffeinated black tea	|__|__|	-9 ☐	-7 ☐

SUBJECT ID | | | | | | | | | | | | | | VISIT NO | | | |

SECTION C: CAFFEINATED GREEN TEA

C1) In your lifetime, have you ever regularly drunk caffeinated green tea, that is, at least once per week for 6 months or longer?

1 ☐ Yes → GO TO C2

0 ☐ No → **(SKIP TO SECTION D)**

-9 ☐ Don't Know → **(SKIP TO SECTION D)**

-7 ☐ Refused → **(SKIP TO SECTION D)**

C2) At what age (or in what year) did you <u>start</u> regularly drinking caffeinated green tea?

	Age started		Year started	Don't know	Refused
Caffeinated green tea	|__|__|	or	|__|__|__|__|	-9 ☐	-7 ☐

C3) At what age (or in what year) did you <u>stop</u> regularly drinking caffeinated green tea?

	Age stopped		Year stopped	Currently drink	Don't know	Refused
Caffeinated green tea	|__|__|	or	|__|__|__|__|	-5 ☐	-9 ☐	-7 ☐

C4) During this time, were there periods totaling 5 or more years when you did NOT regularly drink caffeinated green tea?

1 ☐ Yes

→ C4a) During this time, approximately how many years in total did you NOT regularly drink caffeinated green tea: _____ **yrs**

→ C4b) What ages were you when you did NOT regularly drink caffeinated green tea? (If there were multiple periods when you did not regularly drink, please report each period separately.)

AGE: |__|__| **to** AGE: |__|__|
→ AGE: |__|__| **to** AGE: |__|__|
AGE: |__|__| **to** AGE: |__|__|

0 ☐ No
-9 ☐ Don't Know
-7 ☐ Refused

C5) Averaging over your lifetime, during the time you were regularly drinking caffeinated green tea, about <u>how many cups per week</u> did you drink?

Number of	cups/week	Don't know	Refused
Caffeinated green tea	|__|__|	-9 ☐	-7 ☐

SECTION D: CAFFEINATED SODA

D1) In your lifetime, have you ever regularly drunk caffeinated soda, that is, at least once per week for 6 months or longer?

1 ☐ Yes → GO TO D2

0 ☐ No → **(SKIP TO NEXT FORM)**

-9 ☐ Don't Know → **(SKIP TO NEXT FORM)**

-7 ☐ Refused → **(SKIP TO NEXT FORM)**

SUBJECT ID | | | | | | | | | | | | | | VISIT NO | | | |

D2) At what age (or in what year) did you start regularly drinking caffeinated soda?

	Age started		Year started	Don't know	Refused
Caffeinated soda	|__|__|	or	|__|__|__|__|	-9 ☐	-7 ☐

D3) At what age (or in what year) did you stop regularly drinking caffeinated soda?

	Age stopped		Year stopped	Currently drink	Don't know	Refused
Caffeinated soda	|__|__|	or	|__|__|__|__|	-5 ☐	-9 ☐	-7 ☐

D4) During this time, were there periods totaling 5 or more years when you did NOT regularly drink caffeinated soda?

1 ☐ Yes

→ D4a) During this time, approximately how many years in total did you NOT regularly drink caffeinated soda: _____ **yrs**

→ D4b) What ages were you when you did NOT regularly drink caffeinated soda? (If there were multiple periods when you did not regularly drink, please report each period separately.)

AGE: |__|__| **to** AGE: |__|__|
AGE: |__|__| **to** AGE: |__|__|
AGE: |__|__| **to** AGE: |__|__|

0 ☐ No
-9 ☐ Don't Know
-7 ☐ Refused

D5) Averaging over your lifetime, during the time you were regularly drinking caffeinated soda, about how many cans per week did you drink?

Number of	cans/week	Don't know	Refused
Caffeinated soda	|__|__|	-9 ☐	-7 ☐

PLEASE CONTINUE TO THE NEXT FORM

SUBJECT ID ☐☐☐☐☐☐☐☐☐☐☐☐☐☐ VISIT NO ☐☐☐

INITIALS ☐☐☐ SITE NO ☐☐☐ VISIT DATE ☐☐ ☐☐ ☐☐☐☐
MM DD YYYY

PD RFQ-U – HEAD INJURY OR CONCUSSION

The following questions ask about any head injuries you may have had during your lifetime. Please answer these questions to the best of your ability.

1) Have you ever had a head injury or concussion? These may have occurred during sporting activities, from falls, violence, car accidents, or other accidents. Include injuries from both childhood and adulthood.

1 ☐ Yes

2 ☐ Possibly

0 ☐ No → **(SKIP TO NEXT FORM)**
-9 ☐ Don't Know → **(SKIP TO NEXT FORM)**
-7 ☐ Refused → **(SKIP TO NEXT FORM)**

2) In your lifetime, how many have you had? Give your best estimate.

1 ☐ 1

2 ☐ 2

3 ☐ 3

4 ☐ 4

5 ☐ more than 4

SECTION A. Please answer the following questions about your *FIRST* head injury.

A.1) At what age (or in what year) did the head injury occur?

AGE: |__|__|__| or YEAR: |__|__|__|__|

A.2) Did you lose consciousness from this injury?

1 ☐ Yes

0 ☐ No → **(SKIP TO QUESTION A.4)**
-9 ☐ Don't Know → **(SKIP TO QUESTION A.4)**
-7 ☐ Refused → **(SKIP TO QUESTION A.4)**

A.3) How long were you unconscious?

1 ☐ less than 5 minutes 2 ☐ 5-59 minutes 3 ☐ 1-24 hours 4 ☐ longer than 1 day -9 ☐ Don't Know

SUBJECT ID | | | | | | | | | | | | | | VISIT NO | | |

A.4) Did you have a skull fracture?

1 ☐ Yes 0 ☐ No -9 ☐ Don't Know -7 ☐ Refused

A.5) Did you have a seizure from this injury?

1 ☐ Yes 0 ☐ No -9 ☐ Don't Know -7 ☐ Refused

A.6) Did you have memory loss, amnesia, or trouble thinking from this injury?

1 ☐ Yes 0 ☐ No -9 ☐ Don't Know -7 ☐ Refused

A.7) Were you hospitalized for this injury?

1 ☐ Yes 0 ☐ No -9 ☐ Don't Know -7 ☐ Refused

If you had no other head injuries, check this box ☐ and SKIP TO THE NEXT FORM.

SECTION B. Please answer the following questions about your *NEXT* head injury.

B.1) At what age (or in what year) did this head injury occur?

AGE: |__|__|__| or YEAR: |__|__|__|__|

B.2) Did you lose consciousness from this injury?

1 ☐ Yes

0 ☐ No → **(SKIP TO QUESTION B.4)**
-9 ☐ Don't Know → **(SKIP NEXT TO QUESTION B.4)**
-7 ☐ Refused → **(SKIP TO QUESTION B.4)**

B.3) How long were you unconscious?

1 ☐ less than 5 minutes 2 ☐ 5-59 minutes 3 ☐ 1-24 hours 4 ☐ longer than 1 day -9 ☐ Don't Know

B.4) Did you have a skull fracture?

1 ☐ Yes 0 ☐ No -9 ☐ Don't Know -7 ☐ Refused

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B.5) Did you have a seizure from this injury?

1 ☐ Yes 0 ☐ No -9 ☐ Don't Know -7 ☐ Refused

B.6) Did you have memory loss, amnesia, or trouble thinking from this injury?

1 ☐ Yes 0 ☐ No -9 ☐ Don't Know -7 ☐ Refused

B.7) Were you hospitalized for this injury?

1 ☐ Yes 0 ☐ No -9 ☐ Don't Know -7 ☐ Refused

If you had no other head injuries, check this box ☐ and SKIP TO THE NEXT FORM.

SECTION C. If you had *more than 2* head injuries, briefly describe the others below:

Injury #3) AGE: |__|__|__| or YEAR: |__|__|__|__|

Did you lose consciousness? 1 ☐ Yes 0 ☐ No -9 ☐ Don't Know -7 ☐ Refused

Injury #4) AGE: |__|__|__| or YEAR: |__|__|__|__|

Did you lose consciousness? 1 ☐ Yes 0 ☐ No -9 ☐ Don't Know -7 ☐ Refused

Injury #5) AGE: |__|__|__| or YEAR: |__|__|__|__|

Did you lose consciousness? 1 ☐ Yes 0 ☐ No -9 ☐ Don't Know -7 ☐ Refused

Comments: _____

_____

_____

PLEASE CONTINUE TO THE NEXT FORM

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PD RFQ-U – ANTI-INFLAMMATORY MEDICATION HISTORY

The following questions will ask you about a group of medicines commonly used to treat mild to moderate pain, fever, inflammation, or swelling, and sometimes taken to thin the blood or to protect the heart. These include both over-the-counter and prescription medicines. We will ask about three groups of these medicines (1) ibuprofen-based medicines such as Advil and Motrin; (2) aspirin and (3) other anti-inflammatory medicines.

SECTION 1: IBUPROFEN-BASED NON-ASPIRIN

1) Have you ever *regularly* taken ibuprofen-based non-aspirin medications, that is, at least two pills per week for 6 months or longer? These include ibuprofen, Advil, Motrin, Nuprin, and others.

1 ☐ Yes → GO TO 1a

0 ☐ No → **(SKIP TO 2)**

-9 ☐ Don't Know → **(SKIP TO 2)**

-7 ☐ Refused → **(SKIP TO 2)**

1a) At what age (or in what year) did you start regularly taking an ibuprofen-based medication?

Age started		Year Started	Don't know	Refused
|__|__|	or	|__|__|__|__|	-9 ☐	-7 ☐

1b) At what age (or in what year) did you stop regularly taking an ibuprofen-based medication?

Age stopped		Year Stopped	Currently take	Don't know	Refused
|__|__|	or	|__|__|__|__|	-5 ☐	-9 ☐	-7 ☐

1c) During this time, were there periods totaling 5 years or more when you did NOT regularly take an ibuprofen-based medication?

1 ☐ Yes

→ 1c1) During this time, approximately how many years in total did you NOT regularly take ibuprofen-based medication: ____**yrs**

0 ☐ No

-9 ☐ Don't Know

-7 ☐ Refused

SUBJECT ID | | | | | | | | | | | | | | VISIT NO | | |

1d) Averaging over your lifetime, during the time you were regularly taking an ibuprofen-based medication, about <u>how many pills per week</u> did you take?

Number	of pills/week	Don't know	Refused
Ibuprofen-based medication	|__|__|	-9 ☐	-7 ☐

SECTION 2: ASPIRIN

2) Have you ever *<u>regularly</u>* taken <u>aspirin</u>, that is, at least two pills per week for 6 months or longer?

1 ☐ Yes → GO TO 2a

0 ☐ No → **(SKIP TO 3)**

-9 ☐ Don't Know → **(SKIP TO 3)**

-7 ☐ Refused → **(SKIP TO 3)**

2a) At what age (or in what year) did you <u>start</u> regularly taking aspirin?

Age started		Year Started	Don't know	Refused
|__|__|	or	|__|__|__|__|	-9 ☐	-7 ☐

2b) At what age (or in what year) did you <u>stop</u> regularly taking aspirin?

Age stopped		Year Stopped	Currently take	Don't know	Refused
|__|__|	or	|__|__|__|__|	-5 ☐	-9 ☐	-7 ☐

2c) During this time, were there periods totaling 5 years or more when you did NOT regularly take aspirin?

1 ☐ Yes

→ 2c1) During this time, approximately how many years in total did you NOT regularly take aspirin? _____ **yrs**

0 ☐ No

-9 ☐ Don't Know

-7 ☐ Refused

2d) Averaging over your lifetime, during the time you were regularly taking aspirin, about <u>how many pills per week</u> did you take?

Number of	pills/week	Don't know	Refused
Aspirin |	__|__|	-9 ☐	-7 ☐

SECTION 3: *OTHER* ANTI-INFLAMMATORY MEDICATIONS

3) Have you ever *<u>regularly</u>* taken *<u>other</u>* <u>anti-inflammatory medications</u> for pain, inflammation, or swelling, that is, at least two pills per week for 6 months or longer? Please do NOT include the use of Tylenol or acetaminophen, or narcotic pain relievers such as Vicodin or codeine or demerol.

1 ☐ Yes → GO TO 3a

0 ☐ No → **(SKIP TO NEXT FORM)**

-9 ☐ Don't Know → **(SKIP TO NEXT FORM)**

-7 ☐ Refused → **(SKIP TO NEXT FORM)**

3a) At what age (or in what year) did you <u>start</u> regularly taking other anti-inflammatory medications?

Age started		Year Started	Don't know	Refused
|__|__|	or	|__|__|__|__|	-9 ☐	-7 ☐

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3b) At what age (or in what year) did you <u>stop</u> regularly taking other anti-inflammatory medications?

Age stopped		Year Stopped	Currently take	Don't know	Refused
|__|__|	or	|__|__|__|__|	-5 ☐	-9 ☐	-7 ☐

3c) During this time, were there periods totaling 5 years or more when you did NOT regularly take other anti-inflammatory medicines?

1 ☐ Yes

→ 3c1) During this time, approximately how many years in total did you NOT regularly take other anti-inflammatory medications? ____ **yrs**

0 ☐ No

-9 ☐ Don't Know

-7 ☐ Refused

3d) Averaging over your lifetime, during the time you were regularly taking other anti-inflammatory medications, about <u>how many pills per week</u> did you take?

	Number of pills/week	Don't know	Refused
Other anti-inflammatory medication	|__|__|	-9 ☐	-7 ☐

PLEASE CONTINUE TO THE NEXT FORM

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PD RFQ-U- <u>SMOKING and TOBACCO</u>

The following questions ask about your use of tobacco during your lifetime. Please answer these questions to the best of your ability.

PART I: CIGARETTES

1) In your lifetime, have you smoked 100 or more cigarettes (5 packs)?

1 ☐ Yes
0 ☐ No → **(SKIP TO QUESTION 7)**
-9 ☐ Don't Know → **(SKIP TO QUESTION 7)**
-7 ☐ Refused → **(SKIP TO QUESTION 7)**

2) In your lifetime, have you ever regularly smoked cigarettes, that is, at least one cigarette per day for 6 months or longer?

1 ☐ Yes → GO TO 3

0 ☐ No → **(SKIP TO QUESTION 7)**

-9 ☐ Don't Know → **(SKIP TO QUESTION 7)**

-7 ☐ Refused → **(SKIP TO QUESTION 7)**

3) At what age (or in what year) did you <u>start</u> regularly smoking cigarettes?

Age Started	Year started	Don't know	Refused
|__|__|	or |__|__|__|__|	-9 ☐	-7 ☐

4) At what age (or in what year) did you <u>stop</u> regularly smoking cigarettes?

Age Stopped	Year stopped	Currently smoke	Don't know	Refused
|__|__|	or |__|__|__|__|	-5 ☐	-9 ☐	-7 ☐

SUBJECT ID | | | | | | | | | | | | | | VISIT NO | | |

5) During this time, were there periods totaling 5 or more years when you did NOT regularly smoke cigarettes?

1 ☐ Yes

→ 5a) During this time, approximately how many years in total did you NOT regularly smoke? _____**yrs**

→ 5b) What ages were you when you did not regularly smoke? (If there were multiple periods when you did not regularly smoke, please report each period separately.)

AGE: |__|__| **to** AGE: |__|__|
AGE: |__|__| **to** AGE: |__|__|
AGE: |__|__| **to** AGE: |__|__|

0 ☐ No

-9 ☐ Don't Know

-7 ☐ Refused

6) During the time that you regularly smoked, on average, how much did you smoke <u>per day</u>?

Packs Per day		Cigarettes per day	Don't know	Refused
|__|__|	or	|__|__|	-9 ☐	-7 ☐

PART II: SMOKELESS TOBACCO

7) Have you ever used smokeless tobacco such as chewing tobacco or snuff regularly, that is, at least once per day for 6 months or longer?

1 ☐ Yes

0 ☐ No → **(SKIP TO NEXT FORM)**

-9 ☐ Don't Know → **(SKIP TO NEXT FORM)**

-7 ☐ Refused → **(SKIP TO NEXT FORM)**

SUBJECT ID | | | | | | | | | | | | | | VISIT NO | | |

8) At what age (or in what year) did you <u>start</u> regularly using smokeless tobacco?

Age Started		Year started	Don't know	Refused
|	__|__| or	|__|__|__|__|	-9 ☐	-7 ☐

9) At what age (or in what year) did you <u>stop</u> regularly using smokeless tobacco?

Age Stopped		Year stopped	Currently use	Don't know	Refused
|	__|__| or	|__|__|__|__|	-5 ☐	-9 ☐	-7 ☐

PLEASE CONTINUE TO THE NEXT FORM

SUBJECT ID |__|__|__|__|__|__|__|__|__|__|__|__|__|__| VISIT NO |__|__|__|

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MM DD YYYY

PD RFQ-U - ALCOHOL

The following questions ask about your use of alcohol during your lifetime. Please answer these questions to the best of your ability.

1) In your lifetime, have you drunk 100 or more alcoholic drinks (beer, wine, liquor, spirits)?

1 ☐ Yes

0 ☐ No → **(SKIP TO THE NEXT FORM)**

-9 ☐ Don't Know → **(SKIP TO THE NEXT FORM)**

-7 ☐ Refused → **(SKIP TO THE NEXT FORM)**

2) In your lifetime, have you ever regularly drunk alcohol, that is, at least one drink per week for 6 months or longer?

1 ☐ Yes → GO TO 3

0 ☐ No → **(SKIP TO THE NEXT FORM)**

-9 ☐ Don't Know → **(SKIP TO THE NEXT FORM)**

-7 ☐ Refused → **(SKIP TO THE NEXT FORM)**

3) At what age (or in what year) did you start regularly drinking alcohol?

	Age started		Year started	Don't know	Refused
Alcohol	|__|__|	or	|__|__|__|__|	-9 ☐	-7 ☐

4) At what age (or in what year) did you stop regularly drinking alcohol?

	Age stopped		Year stopped	Currently drink	Don't know	Refused
Alcohol	|__|__|	or	|__|__|__|__|	-5 ☐	-9 ☐	-7 ☐

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5) During this time, were there periods totaling 5 or more years when you did NOT regularly drink alcohol?

1 ☐ Yes

→ 5a) During this time, approximately how many years in total did you NOT regularly drink: _____ **yrs**

→ 5b) What ages were you when you did not regularly drink? (If there were multiple periods when you did NOT regularly drink, please report each period separately.)

AGE: |__|__| **to** AGE: |__|__|
AGE: |__|__| **to** AGE: |__|__|
AGE: |__|__| **to** AGE: |__|__|

0 ☐ No
-9 ☐ Don't Know
-7 ☐ Refused

6) During the years when you regularly drank alcohol, on average, how many servings of each type of alcohol did you drink per week? (A serving of alcohol is one can or bottle of beer, one glass of wine, or one shot of liquor or spirits.)

Number	of servings/week	Never drank	Don't know	Refused
a) Beer	|__|__|	-5 ☐	-9 ☐	-7 ☐
b) Liquor or Spirits	|__|__|	-5 ☐	-9 ☐	-7 ☐
c) Red Wine	|__|__|	-5 ☐	-9 ☐	-7 ☐
d) White Wine	|__|__|	-5 ☐	-9 ☐	-7 ☐

PLEASE CONTINUE TO THE NEXT FORM