

VCP Mutation and Quality of Life Questionnaire

Name _____ Date of Birth _____ Age _____

Mailing Address _____

Phone Number _____ E-mail _____

Diagnosis given by _____ Age at Diagnosis _____

Male Female

1. Is your gene mutation known? Yes (please indicate which mutation you have below)
 Yes, but I can not remember what it is
 No, I have been tested but no mutation was found
 No, I have not been tested

VCP gene mutation

- Arg93Cys 277C>T Arg95Gly 283C>G Arg155Cys 463C>T Arg155His 464G>A
 Arg155Pro 464G>C Arg159His 476G>A Arg191Gln 572G>A Leu198Trp 593T>G
 Ala232Glu 695C>A Asn387His 1159A>C Arg159Cys 475C>T
 Other _____

If you do not know your mutation, do you give UC Irvine permission to look it up at a future date?

- Yes _____ Date _____ No

2. In general would you say your health is?

Excellent Very good Good Fair Poor

3. Other than the symptoms of IBMPFD, would you say your health is

Excellent Very good Good Fair Poor

4. In the past year, how often would you say your physical health (physical illness or injury) was not good?

- All of the time
 Most of the time (several days a week)
 Some of the time (few times a month)
 A little of the time (once in a while)
 None of the time

5. In the past year, how often would you say your mental health (stress, depression, problems with emotions) was not good?

- All of the time
 Most of the time (several days a week)
 Some of the time (few times a month)
 A little of the time (once in a while)
 None of the time

6. Compared to five years ago, how would you rate your health in general now?

- Much better now than before
 Somewhat better now than before
 About the same as before
 Somewhat worse now than before
 Much worse now than before

In the past month,

7. Have you felt relatively happy?

- All of the time
- Most of the time
- Some of the time
- A little of the time
- None of the time

8. Were you nervous or anxious?

- All of the time
- Most of the time
- Some of the time
- A little of the time
- None of the time

9. Have you felt sad or depressed?

- All of the time
- Most of the time
- Some of the time
- A little of the time
- None of the time

10. Have you felt calm and peaceful?

- All of the time
- Most of the time
- Some of the time
- A little of the time
- None of the time

11. Did you have a lot of energy?

- All of the time
- Most of the time
- Some of the time
- A little of the time
- None of the time

12. Did you feel tired or worn out?

- All of the time
- Most of the time
- Some of the time
- A little of the time
- None of the time

13. During the past year, how much of the time has your physical health interfered with your social activities (like visiting friends, playing games, eating out, etc.)?

- All of the time
- Most of the time
- Some of the time
- A little of the time
- None of the time

14. During the past year, how much of the time has your emotional health interfered with your social activities (like visiting friends, playing games, eating out, etc.)?

- All of the time
- Most of the time
- Some of the time
- A little of the time
- None of the time

15. How limited do you currently feel in your activities by physical health problems? (from pain, physical limitations)

- All of the time
- Most of the time
- Some of the time
- A little of the time
- None of the time

16. Do you feel that your physical health as caused you to accomplish less than you would like?

- Yes
- No

17. Do you feel that your physical health has caused you difficulty with work or other activities?

- All of the time
- Most of the time
- Some of the time
- A little of the time
- None of the time

18. How limited do you currently feel in your activities by mental health issues? (from feeling sad, depressed, anxious, or uninterested in usual activities)

- All of the time
- Most of the time
- Some of the time
- A little of the time
- None of the time

19. Do you feel that your mental health as caused you to accomplish less than you would like?

- Yes
- No

20. Do you feel that your mental health has caused you difficulty with work or other activities?

- All of the time
- Most of the time
- Some of the time
- A little of the time
- None of the time

21. How much has pain interfered with your normal activities, recreation, or work?

- A lot, all of the time
- Most of the time
- Some
- A little
- None of the time

22. Do you feel that you seem to get sick a little easier than other people do?

- Yes
- Do not know
- No

23. Do you feel that you are as healthy as everyone else you know?
 Yes Do not know No
24. Do you expect your health to get worse?
 Yes Yes, a little Do not know No, not really No
25. Do you feel that your health is excellent?
 Yes Yes, a little Do not know No, not really No

Age at Onset/Loss of ability

26. Currently, my level of speech ability is:
 normal speech processes _____
 detectable speech disturbance _____
 intelligible with repeating _____
 speech combined with non-vocal communication _____
 loss of useful speech _____
27. My current ability to swallow allows for:
 normal eating habits _____
 early eating problems, occasional choking _____
 dietary consistency changes _____
 needs supplemental tube feedings _____
 NPO (exclusively caregiver feedings) _____
28. My ability to write is:
 normal _____
 slow or sloppy, but all words legible _____
 not all words legible _____
 able to grip pen, unable to write _____
 unable to grip pen _____
29. My current ability to cut food and handle utensils is:
 normal _____
 somewhat slow and clumsy, needs no help _____
 can cut most foods, some help needed _____
 foods cut by someone else, can still feed slowly _____
 needs to be fed _____
30. I feel that my digestion and excretion are/ involves:
 normal _____
 constipation, irregularity _____
 incontinence, or cramps and unformed stool _____
 requires assistance _____
 needs special equipment _____
31. My ability to get dressed and get ready in the morning/night is:
 normal _____
 independent self-care with effort _____
 intermittent assistance or substitute methods _____
 needs attendant for self care _____
 total dependence _____

32. Currently, my ability to sleep at night is:

- normal
- difficult to fall or stay asleep
- frequent awakening (every 2-3 hours)
- can only sleep in one or two positions
- can only sleep with medication

33. My ability to walk is currently:

- normal
- early ambulation difficulties, or drop foot-foot drops and causes tripping
- walks with assistance
- non-ambulatory functional movement only
- no purposeful leg movement

34. My ability to climb stairs is:

- normal
- slow
- mild unsteadiness or fatigue
- needs assistance
- cannot do

35. My ability to rise and stand is:

- normal
- slow or unsteady
- uses arms
- uses mechanical assistance
- cannot stand

36. Currently, my ability to run and jump is/has:

- normal
- loss of jump height
- loss of run speed or distance
- no running or jumping, walking only
- no purposeful leg movement

37. My ability to breathe is currently:

- normal
- shortness of breath with minimal exertion
- shortness of breath at rest
- intermittent ventilator assistance
- ventilator dependent

38. I feel that my sexual functions are:

- normal
- infrequent capability
- loss of capability
- infrequent desire
- loss of desire or interest

39. My muscle atrophy/weakness in my arms involves:

- none
- some weakness in arms
- noticeable weakness in upper arms
- noticeable weakness in lower arms
- inability to use arms

40. My muscle atrophy/weakness in my legs involves:

- none
- some weakness in legs
- noticeable weakness in upper legs
- noticeable weakness in lower legs
- inability to use legs

41. My blood circulation currently involves:

- normal
- slight pressure reduces circulation
- chills in extremities
- chilled extremities needs external heat source
- need mechanical circulation assistance

42. I have cramps and tremors:

- none/nowhere
- tremors/spasms in legs or arms
- cramps in legs or arms
- tremors or cramps in other muscles
- no voluntary muscle control

43. My level of body pain is:

- normal/average
- occasional mild-moderate pain
- occasional moderate- severe pain
- frequent severe pain
- constant pain, requiring medication

The pain is located _____

and occurs _____

44. I have numbness and tingling:

- none/nowhere
- numbness in extremities
- tingling in extremities
- long-term numbness or tingling
- permanent numbness or tingling

45. My Paget's disease current diagnosis is:

- none/normal
- elevated blood test results
- visible on X-ray
- joint pain

46. My symptoms of memory loss are:

- none/normal _____
- some short term memory loss _____
- frequent short-term memory loss _____
- some long term memory loss _____
- loss of short term and long-term memory _____

47. My symptoms of cogitative loss are:

- none/normal _____
- reduced ability to focus on specific analytical tasks _____
- reduced ability to concentrate for normal periods of time _____
- minor personality changes _____
- major personality changes _____

Do you have any of the following problems in your family?

(please list relationship, e.g., maternal uncle, paternal grandmother, etc., and age in years, if known)

48. ORGANS

	Relationship	Age
<input type="checkbox"/> Cardiac problems	_____	_____
<input type="checkbox"/> Cardiomyopathy	_____	_____
<input type="checkbox"/> EKG changes	_____	_____
<input type="checkbox"/> Liver problems	_____	_____
<input type="checkbox"/> Elevated liver enzymes	_____	_____
<input type="checkbox"/> Gall bladder problems	_____	_____
<input type="checkbox"/> Cataracts	_____	_____
<input type="checkbox"/> Glaucoma	_____	_____

49. LOSS OF PHYSICAL DEVELPOMENT

- Walking _____
- Talking _____
- Competitive individual sports _____
- Competitive team sports _____
- Regular exercise/stretching schedule _____

50. SPORTS RELATED INJURIES

- Broken bones _____
- Sprains/strains _____
- Arthritis/tendonitis _____
- Concussion _____

51. DIAGNOSIS HISTORY

- Noticing body not performing correctly _____
- Medical confirmation of physical deterioration _____
- Medical evidence (Cpk) of muscle loss _____
- EMG tests _____
- MRI tests _____
- DNA tests _____
- Muscle Biopsy _____

52. PRIOR EXPLANATIONS

- Getting old _____
- Middle age crisis _____
- Adult child of alcoholic _____
- Unknown neuromuscular disorder _____
- FSH or LG _____
- Other (explain) _____

53. What is your height? _____

54. What is your weight? _____

55. In the activities you do in a typical week, how long do you do moderate physical exercise (such as brisk walking, bicycling, vacuuming, or gardening)? _____

56. In the activities you do in a typical week, how long do you do vigorous physical exercise (such as running, aerobics, strenuous sports, heavy yard work)? _____

57. How tired/fatigue do you usually feel in an average week?
 not at all a little some fairly tired very tired

58. How much pain do you feel in an average week currently?
 not at all a little some pain fair amount a lot of pain

59. Do you feel that you are limited from participating in moderate activities due to your health?
 Yes, limited a lot Yes, limited a little No, not limited at all

59a. (If applicable) Do you feel that after moderate exercise, you feel more or less fatigue than normal?
 less tired the same more tired

60. Do you feel that you are limited from participating in vigorous activities due to your health?
 Yes, limited a lot Yes, limited a little No, not limited at all

60a. (If applicable) Do you feel that after vigorous exercise, you feel more or less fatigue than normal?
 less tired the same more tired

61. Do you feel that you are limited from lifting or carrying groceries due to your health?
 Yes, limited a lot Yes, limited a little No, not limited at all

62. Do you feel that you are limited from climbing stairs due to your health?
 Yes, limited a lot Yes, limited a little No, not limited at all

63. Do you feel that you are limited from bending or kneeling due to your health?
 Yes, limited a lot Yes, limited a little No, not limited at all

64. Do you feel that you are limited from walking short distances due to your health?
 Yes, limited a lot Yes, limited a little No, not limited at all

65. Do you feel that you are limited from walking long distances (over a mile) due to your health?
 Yes, limited a lot Yes, limited a little No, not limited at all

66. Do you take multivitamins? If yes, what type? _____

66a. How often? _____

67. Do you take any other supplements? (calcium, protein bars, etc) If yes, please list name, the amount taken, and the primary reason for the supplements.

68. Do you take any other medication? If yes, please list name, the amount taken, and the primary reason for the medication (pain, etc).

69. Do you smoke? _____ If so, how often? _____

70. How often do you drink alcoholic beverages per week? _____ # drinks per week? _____

71. In a typical weekday, how often do you eat one serving of green vegetables? (1 serving = 1 cup of raw leafy vegetables, 1/2 cup of other vegetables, cooked or raw, 3/4 cup of vegetable juice):

none once twice 3 times 4 times 5 times

72. In a typical weekday, how often do you eat one serving of fruits? (1 serving = One medium apple, orange or banana, 1/2 cup of chopped, cooked or canned fruit, 3/4 cup of fruit juice):

none once twice 3 times 4 times 5 times

73. In a typical weekday, how often do you eat one serving of white bread, rice, pasta, or potatoes? (1 serving = One slice of bread, 1 ounce of ready-to-eat cereal, 1/2 cup of cooked cereal, rice or pasta:

none once twice 3 times 4 times 5 times

74. In a typical weekday, how often do you eat one serving of fish/chicken? (1 serving = 2-3 oz, about the size of a deck of cards):

none once twice 3 times 4 times 5 times

75. In a typical weekday, how often do you eat 1 serving of meat? (1 serving = 2-3 oz, about the size of a deck of cards):

none once twice 3 times 4 times 5 times

76. In a typical weekday, how often do you eat 1 serving of dairy products? (1 serving = 1 cup of milk or yogurt, 1 1/2 ounce of natural cheese, 1 ounce of process cheese):

none once twice 3 times 4 times 5 times

77. In a typical weekday, how often do you eat 1 serving of nuts, eggs, or beans? (1 serving = 1 egg, 2 tablespoons of peanut butter, 1/2 cup cooked dry beans, 1/3 cup of nuts):

none once twice 3 times 4 times 5 times

78. In a typical weekday, how often do you eat one serving of sweets, fats, and oil? (1 serving = 1 teaspoon butter or margarine, 12oz soda, 1 teaspoon sugar, 1 table spoon salad dressing, 1 teaspoon jam/jelly):

none once twice 3 times 4 times 5 times