

Name: _____ Date of Birth: _____

Home address: _____

Home phone number: _____ Alternative number: _____

Local physician's name: _____ Physician's phone number: _____

Do we have your permission to contact your local physician? Yes No

Marital Status (please circle one) Single Married Separated Divorced Widowed

Do you have any children? Yes No

If yes, how many? _____ What are your children's ages? _____

What is the highest level of education that you have attained? (please check one)

- Some high school (no degree) Completed high school
 Some college (no degree) Associates degree
 Bachelor's degree Graduate degree

What is your occupation? _____

What is your ethnic background? (please check the one that best applies)

- American Indian, Eskimo, Aleut Pacific Islander
 Asian Caucasian
 Black Two or more ethnic backgrounds
 Hispanic

How concerned are you about developing the following yourself?

	Not at all	A little	Somewhat	Very	Extremely
Myopathy (Muscle)	1	2	3	4	5
Paget disease of bone	1	2	3	4	5
Frontotemporal dementia	1	2	3	4	5

How concerned are you about the following in your family?

	Not at all	A little	Somewhat	Very	Extremely
Myopathy (Muscle)	1	2	3	4	5
Paget disease of bone	1	2	3	4	5
Frontotemporal dementia	1	2	3	4	5

What do you think is the chance that you have this genetic change? _____%

Do you wish to know if you have a genetic change that leads to *Inclusion body myopathy associated with Paget disease of bone and frontotemporal dementia (IBMPFD)* in your family?

- Yes (please complete questions 1-3) No (please complete questions 4-5)

If you WANT to know your genetic status, please complete the following questions:

1) What is the most important reason for you to want to know your genetic status? _____

2) In deciding to be tested for IBMPFD, please rate how important the following potential reasons are to you? Not at all A little Somewhat Very Extremely

Relieving uncertainty	1	2	3	4	5
General planning for the future	1	2	3	4	5
Being able to inform my children about their risks	1	2	3	4	5
Being able to make arrangements for my future care	1	2	3	4	5
To plan for suicide, if the results are positive	1	2	3	4	5
To relieve anxiety	1	2	3	4	5
To alter the medical care I currently receive	1	2	3	4	5
To confirm the feeling that I already have the disease	1	2	3	4	5
Planning a family	1	2	3	4	5
Curiosity	1	2	3	4	5
Other: _____	1	2	3	4	5

3) Please rank the following aspects of the condition in how important they are in your decision to be tested (with 1 being the most important through 3 being the least important)

_____ Myopathy (Muscle) _____ Paget disease of bone _____ Frontotemporal Dementia

If you DO NOT want to know your genetic status, please complete the following questions:

4) What is the most important reason for you to NOT want to know your genetic status? _____

5) In deciding NOT to be tested for IBMPFD, please rate how important the following potential reasons are to you? Not at all A little Somewhat Very Extremely

The results would be too difficult to handle	1	2	3	4	5
The results would not alter my medical care	1	2	3	4	5
The results would not affect my future planning	1	2	3	4	5
There is nothing that can be done anyways	1	2	3	4	5
It would make me worry about my children's risks of developing IBMPFD	1	2	3	4	5
I would not be able to continue enjoying life	1	2	3	4	5
The results could change how people treat me	1	2	3	4	5
Insurance companies can misuse my information	1	2	3	4	5
I would just be preoccupied with the signs of onset of the disease	1	2	3	4	5
Other: _____	1	2	3	4	5

Hospital Anxiety and Depression Scale (HADS)

Scale items:

Anxiety subscale:

1. I feel tense or "wound up."
 1. Most of the time
 2. A lot of the time
 3. From time to time, occasionally
 4. Not at all
2. I still enjoy the things I used to enjoy.
 1. Definitely as much
 2. Not quite as much
 3. Only a little
 4. Hardly at all
3. I get a sort of frightened feeling as if something awful is about to happen.
 1. Very definitely and quite badly
 2. Yes, but not too badly
 3. A little, but it doesn't worry me
 4. Not at all
4. I can laugh and see the funny side of things.
 1. As much as I always could
 2. Not quite so much now
 3. Definitely not so much now
 4. Not at all
5. Worrying thoughts go through my mind.
 1. A great deal of the time
 2. A lot of the time
 3. From time to time but not too often
 4. Only occasionally
6. I feel cheerful.
 1. Not at all
 2. Not often
 3. Sometimes
 4. Most of the time
7. I can sit at ease and feel relaxed.
 1. Definitely
 2. Usually
 3. Not often
 4. Not at all
8. I feel as if I am slowed down.
 1. Nearly all the time
 2. Very often
 3. Sometimes
 4. Not at all

9. I get a sort of frightened feeling like "butterflies" in the stomach.
 1. Not at all
 2. Occasionally
 3. Quite often
 4. Very often
10. I have lost interest in my appearance.
 1. Definitely
 2. I don't take so much care as I should
 3. I may not take quite as much care
 4. I take just as much care as ever
11. I feel restless as if I have to be on the move.
 1. Very much indeed
 2. Quite a lot
 3. Not very much
 4. Not at all
12. I look forward with enjoyment to things.
 1. As much as I ever did
 2. Rather less than I used to
 3. Definitely less than I used to
 4. Hardly at all
13. I get sudden feelings of panic.
 1. Very often indeed
 2. Quite often
 3. Not very often
 4. Not at all
14. I can enjoy a good book or radio or TV program.
 1. Often
 2. Sometimes
 3. Not often
 4. Very seldom