

## IBMPFD Symptoms List

Patient Name  
or ID: \_\_\_\_\_

Date of List  
Completion \_\_\_\_\_

Patient DOB: \_\_\_\_\_

Completed by: \_\_\_\_\_

Sex of Patient \_\_\_\_\_

<p><b>1. SPEECH</b> <span style="float: right;"><b>Age at Onset</b></span></p> <p>4 normal speech processes _____</p> <p>3 detectable speech disturbance _____</p> <p>2 intelligible with repeating _____</p> <p>1 speech combined with non-vocal communication _____</p> <p>0 loss of useful speech _____</p>	<p><b>10. WALKING</b> <span style="float: right;"><b>Age at Onset</b></span></p> <p>4 normal _____</p> <p>3 early ambulation difficulties _____</p> <p>2 walks with assistance _____</p> <p>1 non-ambulatory functional movement only _____</p> <p>0 no purposeful leg movement _____</p>
<p><b>2. SWALLOWING</b></p> <p>4 normal eating habits _____</p> <p>3 early eating problems, occasional choking _____</p> <p>2 dietary consistency changes _____</p> <p>1 needs supplemental tube feedings _____</p> <p>0 NPO (exclusively caregiver feedings) _____</p>	<p><b>11. CLIMBING STAIRS</b></p> <p>4 normal _____</p> <p>3 slow _____</p> <p>2 mild unsteadiness or fatigue _____</p> <p>1 needs assistance _____</p> <p>0 cannot do _____</p>
<p><b>3. HANDWRITING</b></p> <p>4 normal _____</p> <p>3 slow or sloppy, all words legible _____</p> <p>2 not all words legible _____</p> <p>1 able to grip pen, unable to write _____</p> <p>0 unable to grip pen _____</p>	<p><b>12. STANDING</b></p> <p>4 normal _____</p> <p>3 slow or unsteady _____</p> <p>2 uses arms _____</p> <p>1 uses mechanical assistance _____</p> <p>0 cannot stand _____</p>
<p><b>4. CUTTING FOOD AND HANDLING UTENSILS</b></p> <p>4 normal _____</p> <p>3 somewhat slow and clumsy, needs no help _____</p> <p>2 can cut most foods, some help needed _____</p> <p>1 foods cut by someone else, can still feed slowly _____</p> <p>0 needs to be fed _____</p>	<p><b>13. RUNNING AND JUMPING</b></p> <p>4 normal _____</p> <p>3 loss of jump height _____</p> <p>2 loss of run speed or distance _____</p> <p>1 no running or jumping, walking only _____</p> <p>0 no purposeful leg movement _____</p>
<p><b>5. DIGESTION AND EXCRETION</b></p> <p>4 normal _____</p> <p>3 constipation, irregularity _____</p> <p>2 incontinence _____</p> <p>1 requires assistance _____</p> <p>0 needs special equipment _____</p>	<p><b>14. BREATHING</b></p> <p>4 normal _____</p> <p>3 shortness of breath with minimal exertion _____</p> <p>2 shortness of breath at rest _____</p> <p>1 intermittent ventilator assistance _____</p> <p>0 ventilator dependent _____</p>
<p><b>6. SEXUAL FUNCTIONS</b></p> <p>2 normal _____</p> <p>1.5 infrequent capability _____</p> <p>1 loss of capability _____</p> <p>.5 infrequent desire _____</p> <p>0 loss of desire or interest _____</p>	<p><b>15. LOCATION OF MUSCLE ATROPHY</b></p> <p>4 none _____</p> <p>3 reduction of strength/mass in upper legs _____</p> <p>2 reduction of strength/mass in upper arms _____</p> <p>1 no usable extremities _____</p> <p>0 no voluntary muscle control _____</p>
<p><b>7. DRESSING AND HYGIENE</b></p> <p>4 normal _____</p> <p>3 independent self care with effort _____</p> <p>2 intermittent assistance or substitute methods _____</p> <p>1 needs attendant for self care _____</p> <p>0 total dependence _____</p>	<p><b>16. BLOOD CIRCULATION</b></p> <p>2 normal _____</p> <p>1.5 slight pressure reduces circulation _____</p> <p>1 chills in extremities _____</p> <p>.5 chilled extremities needs external heat source _____</p> <p>0 need mechanical circulation assistance _____</p>
<p><b>8. TURNING IN BED AND ADJUSTING BEDCLOTHES</b></p> <p>4 normal _____</p> <p>3 somewhat slow or clumsy, needs no help _____</p> <p>2 can turn alone or adjust sheets with difficulty _____</p> <p>1 can initiate, cannot turn or adjust sheets _____</p> <p>0 helpless _____</p>	<p><b>17. CRAMPS AND TREMORS</b></p> <p>2 none _____</p> <p>1.5 tremors/spasms in legs or arms _____</p> <p>1 cramps in legs or arms _____</p> <p>.5 tremors or cramps in other muscles _____</p> <p>0 no voluntary muscle control _____</p>
<p><b>9. SLEEPING</b></p> <p>4 normal _____</p> <p>3 difficult to fall or stay asleep _____</p> <p>2 frequent awakening _____</p> <p>1 can only sleep in 1 or 2 positions _____</p> <p>0 can only sleep with medication _____</p>	<p><b>18. NUMBNESS AND TINGLING</b></p> <p>2 none _____</p> <p>1.5 numbness in extremities _____</p> <p>1 tingling in extremities _____</p> <p>.5 long term numbness or tingling _____</p> <p>0 permanent numbness or tingling _____</p>

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<b>17. PAGET DISEASE</b> <span style="float: right;"><b>Age at Onset</b></span> 4 normal _____ 3 elevated blood test results _____ 2 visible on X-ray _____ 1 joint pain _____ 0 visible joint deformities _____	<b>18. FRONTOTEMPORAL DEMENTIA</b> <span style="float: right;"><b>Age at Onset</b></span> 4 normal _____ 3 personality changes _____ 2 some memory loss _____ 1 frequent memory loss _____ 0 cannot communicate _____
<b>The following questions are regarding possible other associated problems, family history, and diagnosis history</b>	
<b>1. ORGANS (circle appropriate)</b> Cardiac problems Cardiomyopathy EKG changes Liver problems Elevated liver enzymes Gall bladder problems Cataracts Glaucoma	<b>2. FAMILY HISTORY OF ORGAN PROBLEMS</b> Cardiac problems Cardiomyopathy EKG changes Liver problems Elevated liver enzymes Gall bladder problems Cataracts Glaucoma
<b>3. PHYSICAL DEVELOPMENT</b> <span style="float: right;"><b>Age (stop)</b></span> Walking _____ Talking _____ Competitive individual sports _____ Competitive team sports _____ Regular exercise/stretching schedule _____	<b>4. SPORTS RELATED INJURIES</b> <span style="float: right;"><b>Age at Onset</b></span> Broken bones _____ Sprains/strains _____ Torn ligaments/tendons _____ Arthritis/tendonitis _____ Concussion _____
<b>5. DIAGNOSIS HISTORY</b> <span style="float: right;"><b>Age</b></span> Noticing body not performing correctly _____ Medical confirmation of physical deterioration _____ Medical evidence (Cpk) of muscle loss _____ EMG tests _____ MRI tests _____ DNA tests _____ Muscle Biopsy _____	<b>6. PRIOR EXPLANATIONS</b> <span style="float: right;"><b>Age</b></span> Getting old _____ Middle age crisis _____ Adult child of alcoholic _____ Unknown neuromuscular disorder _____ FSH or LG _____ Other _____
<b>7. LOCATION OF MUTATION</b> p.Arg93Cys 277C>T _____ p.Arg95Gly 283C>G _____ p.Arg155Cys 463C>T _____ p.Arg155His 464G>A _____ p.Arg155Pro 464G>C _____ p.Arg159His 476G>A _____ p.Arg191Gln 572G>A _____ p.Leu198Trp 593T>G _____ p.Ala232Glu 695C>A _____ p.Asn387His 1159A>C _____	