

TABLE S1. SURVEY QUESTIONS AND SUPPLEMENTAL SURVEY

Q1. Informed Consent

Q2. Year and Place of Birth: (Please fill in each to the best of your knowledge)

Year Born: _____

City of Birth: _____

State of Birth: _____

Country of Birth: _____

Q3. Gender: (Check one)

Male

Female

Q4. Ethnicity – Please specify your ethnicity: (Check one box)

Hispanic or Latino

Not Hispanic or Latino

Q5. Race – Please specify your race: (Check all that apply)

American Indian or Alaska Native

Asian

Black or African American

Native Hawaiian or Other Pacific Islander

White

Q6. Height: (Please fill in)

_____ feet _____ inches

Q7. Current weight: (Please fill in)

_____ pounds

Q8. Please check the highest educational level you finished: (Check one)

- 8th grade or less
- Some High School
- High School graduate or GED
- Some College or Junior College
- 2-year College Degree (Associates)
- 4-year College Degree (BA, BS)
- Masters Degree
- Doctoral Degree
- Professional Degree (MD, JD, etc.)

Q9. Please check the box with your total household annual income before taxes: (Check one)

- \$25,000 or less
- Above \$25,000 but below \$75,000
- Above \$75,000 but below \$150,000
- Above \$150,000
- Prefer not to answer

Q10. Please check your current marital status: (Check one)

- Married
- Separated
- Divorced
- Widowed
- Never married

Q11. Do you currently live in (check one)...

- A house or apartment
- A relative's residence
- An assisted living residence
- Other – Please specify: _____

Q12. Do you live (check one)...

- Alone
- With spouse
- With other relative
- With a friend
- With unmarried partner
- With other person – Please specify: _____

Q13. Employment Status: Are you currently working? (Check one)

- Working Full-time
- Working Part-time
- Unemployed (skip the next question)
- Retired (skip the next question)

Q13a. If you answered working full or part-time in the previous question, are you (check one)...

- Self-employed
- Employed by someone other than yourself

Q14. What symptom(s) of IBM brought you to the doctor? (Check all that apply)

- Trouble Swallowing
- Impaired use of arms and legs
- Weakness
- Fatigue
- Falls
- Difficulty climbing stairs
- Other – Please specify: _____

Q15. How long was the time between your first observed symptoms and your first doctor's diagnosis? (Check one)

- 1-3 Months
- 3-6 Months
- 6-12 Months
- 1-2 Years
- 2 or more Years
- Not applicable

Q16. What was your first diagnosis? (Check one)

- IBM
- Polymyositis
- Arthritis
- Do not know
- Other – Please specify: _____

Q17. Which Physician gave you this diagnosis? (Check one)

- Primary Care
- Neurologist
- Rheumatologist
- Other – Please specify: _____

Q18. If the first diagnosis was incorrect, how much time was there between it and the correct diagnosis? (Please fill in)

Months – Specify: _____

Years – Specify: _____

Q19. Which Physician was the first to diagnose your disease as IBM? (Check one)

- Primary Care
- Neurologist
- Rheumatologist
- Other – Please specify: _____

Q20. Did you have a biopsy at that time? (Check one)

- Yes
- No
- Don't know

Q21. Within three years before your first diagnosis of IBM, did you have any other major medical problem(s)? (Check all that apply)

- Cancer
- Heart
- Arthritis
- Do not know
- Other – Please specify: _____

Q22. Aside from IBM, how would you describe your health? (Check one)

- Excellent
- Very Good
- Good
- Fair
- Poor
- Very Poor
- Bad

Q23. How many times a year do you see a physician specifically concerning IBM? (Check one)

- Zero
- One
- Two
- More – Please specify number: _____

Q24. What Physician(s) do you see specifically concerning IBM? (Check all that apply)

- Neurologist
- Rheumatologist
- Other – Please specify: _____

Q25. Has your doctor recommended any medications, vitamins or food supplements as potentially relevant to your IBM treatment? (Check one)

- Yes
- No

If you answered “Yes”, please answer Question 25a below. If you answered “No”, please skip to Question 26.

Q25a. If you answered yes above, please check the box corresponding with any recommended medications and vitamins you currently use and please record the your daily dosage in the space provided. (Check and fill in all that apply)

- Prednisone _____
- Vitamin B _____
- Vitamin C _____
- Vitamin D _____
- Vitamin E _____
- Multivitamins _____
- Other _____
- None

Q26. Do you actively exercise, including physical therapy and all other exercises?

Yes

No

If you answered “Yes” above, please answer Questions 26a and 26b below. If you answered “No” above, please skip to Question 27.

Q26a. How many hours per week do you generally exercise, including physical therapy and all other exercises? (Please check one)

More than 0 but less than 5 hours per week

At least 5 hours but less than 10 hours per week

More than 10 hours per week

Q26b. What exercises do you do? (Check all that apply)

Physical Therapy

Swimming

Other – Please specify: _____

Questions 27-36 are based primarily on the IBM functional rating scale with some extra considerations. Please select one answer for each question.

Q27. SWALLOWING: (Check one)

Normal

Early eating problems--occasional choking

Dietary consistency changes

Frequent choking

Needs tube feeding

Not applicable

Q28. HANDWRITING (with dominant hand prior to IBM onset): (Check one)

- Normal
- Slow or sloppy; all words are legible
- Not all words are legible
- Able to grip pen but unable to write
- Unable to grip pen
- Not applicable

Q29. CUTTING FOOD AND HANDLING UTENSILS

- Normal
- Somewhat slow and clumsy, but no help needed
- Can cut most foods, although clumsy and slow; some help needed
- Food must be cut by someone, but can still feed slowly
- Needs to be fed
- Not applicable

Q30. FINE MOTOR TASKS (opening doors, using keys, picking up small objects)

- Independent
- Slow or clumsy in completing task
- Independent but requires modified techniques or assistive devices
- Frequently requires assistance from caregiver
- Unable
- Not applicable

Q31. DRESSING

- Normal
- Independent but with increased effort or decreased efficiency
- Independent but requires assistive devices or modified techniques (Velcro snaps, shirts without buttons, etc.)
- Requires assistance from caregiver for some clothing items
- Total dependence
- Not applicable

Q32. HYGIENE (Bathing and Toileting): (Check one)

- Normal
- Independent but with increased effort or decreased activity
- Independent but requires use of assistive devices (Shower chair, raised toilet seat, etc.)
- Requires occasional assistance from caregiver
- Complete dependence
- Not applicable

Q33. TURNING IN BED AND ADJUSTING COVERS

- Normal
- Somewhat slow and clumsy but no help needed
- Can turn alone or adjust sheets, but with great difficulty
- Can initiate, but not turn or adjust sheets alone
- Unable or requires total assistance
- Not applicable

Q34. SIT TO STAND

- Independent (without use of arms)
- Performs with substitute motions (leaning forward, rocking) but without use of arms
- Requires use of arms
- Requires assistance from a device or person
- Unable to stand
- Not applicable

Q35. WALKING

- Normal
- Slow or mild unsteadiness
- Intermittent use of an assistive device (ankle-foot orthotic device or AFO, cane, crutches, walker, etc.)
- Dependent on assistive device
- Wheelchair dependent
- Not applicable

Q36. CLIMBING STAIRS

- Normal
- Slow with hesitation or increased effort; uses hand rail intermittently
- Dependent on hand rail
- Dependent on hand rail and additional support (cane or person)
- Cannot climb stairs
- Not applicable

ASSISTANCE WITH DAILY LIVING QUESTIONS

Q37. Approximately what percentage of your usual living routine is _____? (Please fill in the percentage for each answer below)

still done by you? _____%

done by your spouse, other family or friends? _____% done by paid

household help? _____%

done by paid healthcare help? _____%

TOTAL OF ALL ANSWERS SHOULD EQUAL

100%

Q38. What is your walking ability? (Check one)

- More than a mile
- 1/2 to 1 mile
- 1/4 to 1/2 mile
- A city block or two
- Less than a city block

Q39. Within the last month, which mode(s) of transportation have you used? (Check all that apply)

- Self driven auto
- Auto driven by other
- Train
- Airplane
- Public Bus or Subway
- Other – Please specify: _____
- Not applicable

Q40. In the last year how many days have you been away from home? (Check one)

- Less than 7 days
- At least 7 days but less than 30 days
- At least 30 days but less than 90 days
- 90 days or more

Q41. During the past year, how much did your IBM interfere with your normal work (including both work outside the home and housework)? (Check one)

- Not at all
- Slightly
- Somewhat
- Considerably
- Extremely
- Not applicable

Q42. Do you feel that IBM has influenced your energy levels? (Check one)

- Not at all
- Scarcely
- Some of the time
- Most of the time
- All of the time
- Not applicable

Q43. Do you feel that IBM has influenced your mood towards depression?

- Not at all
- Scarcely
- Some of the time
- Most of the time
- All of the time
- Not applicable

Q44. Have you or do you know anyone who has had a remission from IBM?

- Yes
- No

Q45. Is there a question that you feel to be important that has been left out?

- Yes
- No

If you answered “Yes”, please answer Question 45a below. If you answered “No”, please skip to Questions 46.

Q45a. If yes, please specify which additional question(s) should be asked:

Q46. Additional feedback is welcome. If you have any additional feedback, please provide it in the space below:

SUPPLEMENTAL SURVEY

Year and Place of Birth

Q1. Year Born (yyyy)

City of Birth

State of Birth

Country of Birth

Q2. What year did you first have symptoms that were likely related to IBM?

Q3. What year were you diagnosed with IBM?

Accepted Article

TABLE S2. GENERAL DEMOGRAPHICS

| Patient characteristic | Respondents (n) | Responding Yes (%) |
|---|------------------------|---------------------------|
| Ethnicity | 904 | |
| Hispanic or Latino | 24 | 2.7 |
| Not Hispanic or Latino | 880 | 97.3 |
| Race | 908 | |
| American Indian or Alaska Native | 6 | 0.7 |
| Asian | 13 | 1.4 |
| Black or African American | 21 | 2.3 |
| Native Hawaiian or Other Pacific Islander | 1 | 0.1 |
| White | 867 | 95.5 |
| Marital Status | 914 | |
| Married | 710 | 77.6 |
| Separated | 6 | 0.7 |
| Divorced | 72 | 7.9 |
| Widowed | 92 | 10.1 |
| Never married | 34 | 3.7 |
| Current Living Domicile | 913 | |
| A house or apartment | 837 | 91.7 |
| A relative's residence | 20 | 2.2 |
| An assisted living residence | 26 | 2.8 |
| Other | 30 | 3.3 |
| Current Living Status | 915 | |
| Alone | 124 | 13.6 |
| With spouse | 692 | 75.6 |
| With other relative | 40 | 4.4 |
| With a friend | 11 | 1.2 |
| With unmarried partner | 21 | 2.3 |
| With other person | 27 | 2.9 |
| Employment Status | 910 | |
| Full-time | 108 | 11.8 |
| Part-time | 57 | 6.3 |
| Unemployed | 60 | 6.6 |
| Retired | 685 | 75.3 |

| Patient characteristic | Respondents (n) | Responding Yes (%) |
|---|------------------------|---------------------------|
| Clarify, If Full or Part-Time | 163 | |
| Self-employed | 51 | 31.3 |
| Employed by someone other than yourself | 112 | 68.7 |
| Weight in pounds | 897 | |
| <120 | 60 | 7.0 |
| 120-150 | 174 | 19.0 |
| 150-180 | 219 | 24.0 |
| 180-210 | 230 | 26.0 |
| 210-240 | 131 | 15.0 |
| 240-270 | 59 | 7.0 |
| >=270 | 24 | 3.0 |
| Height in feet | 912 | |
| <4'11 | 8 | 1.0 |
| 4'11-5'2 | 27 | 3.0 |
| 5'2-5'5 | 104 | 11.0 |
| 5'5-5'7 | 170 | 19.0 |
| 5'7-5'10 | 263 | 29.0 |
| 5'10-6'1 | 201 | 22.0 |
| 6'1-6'4 | 119 | 13.0 |
| >=6'4 | 20 | 2.0 |
| BMI Index | 897 | |
| <15 | 4 | 0 |
| 15-18 | 21 | 2.0 |
| 18-21 | 98 | 11.0 |
| 21-24 | 181 | 20.0 |
| 24-27 | 221 | 25.0 |
| 27-30 | 185 | 21.0 |
| 30-33 | 89 | 10.0 |
| >=33 | 98 | 11.0 |

TABLE S3. DAILY LIVING AND AMBULATION

| Patient characteristic | Respondents (n) | Responding Yes (%) |
|---|------------------------|---------------------------|
| Exercise | 912 | 46.6 |
| Physical therapy | 181 | 33.0 |
| Swimming | 65 | 11.8 |
| Other | 303 | 55.2 |
| Swallowing | 905 | |
| Normal | 332 | 36.7 |
| Choking | 399 | 44.1 |
| Dietary consistency changes | 31 | 3.4 |
| Frequent choking | 109 | 12.0 |
| Needs tube feeding | 34 | 3.8 |
| Handwriting | 914 | |
| Normal | 409 | 44.7 |
| Slow or sloppy | 329 | 36.0 |
| Not all words legible | 107 | 11.7 |
| Able to grip pen but unable to write | 26 | 2.8 |
| Unable to grip pen | 41 | 4.5 |
| Not applicable | 2 | 0.2 |
| Cutting Food and Handling Utensils | 894 | |
| Normal | 219 | 24.5 |
| Somewhat slow and clumsy, but no help needed | 323 | 36.1 |
| Can cut most foods, although slow and clumsy; some help needed | 200 | 22.4 |
| Food must be cut by someone, but can still feed slowly | 130 | 14.5 |
| Needs to be fed | 22 | 2.5 |
| Fine Motor Tasks | 911 | |
| Independent | 240 | 26.3 |
| Slow or clumsy in completing task | 288 | 31.6 |
| Independent but requires modified techniques or assistive devices | 204 | 22.4 |
| Frequently requires assistance from caregiver | 132 | 14.5 |
| Unable | 47 | 5.2 |

| Patient characteristic | Respondents (n) | Responding Yes (%) |
|--|------------------------|---------------------------|
| Dressing | 913 | |
| Normal | 152 | 16.6 |
| Independent but with increased effort of decreased efficiency | 349 | 38.2 |
| Independent but requires assistive devices or modified techniques (Velcro snaps, shirts without buttons, etc.) | 116 | 12.7 |
| Requires assistance from caregiver for some clothing items | 189 | 20.7 |
| Total dependence | 106 | 11.6 |
| Not applicable | 1 | 0.1 |
| Hygiene | 912 | |
| Normal | 185 | 20.3 |
| Independent but with increased effort or decreased activity | 168 | 18.4 |
| Independent but requires use of assistive devices (shower chair, raised toilet seat, etc.) | 323 | 35.4 |
| Requires occasional assistance from caregiver | 116 | 12.7 |
| Complete dependence | 120 | 13.2 |
| Turning in Bed and Adjusting Covers | 913 | |
| Normal | 160 | 17.5 |
| Somewhat slow and clumsy but no help needed | 322 | 35.3 |
| Can turn alone or adjust sheets, but with great difficulty | 286 | 31.3 |
| Can initiate, but not turn or adjust sheets alone | 48 | 5.3 |
| Unable or requires total assistance | 95 | 10.4 |
| Not applicable | 2 | 0.2 |
| Sit to Stand | 913 | |
| Independent (without use of arms) | 26 | 2.8 |
| Performs with substitute motions (leaning forward, rocking) but without use of arms | 35 | 3.8 |
| Requires use of arms | 406 | 44.5 |
| Requires assistance from a device or person | 312 | 34.2 |
| Unable to stand | 133 | 14.6 |
| Not applicable | 1 | 0.1 |
| Walking | 914 | |
| Normal | 52 | 5.7 |
| Slow or mild unsteadiness | 155 | 17.0 |

| Patient characteristic | Respondents (n) | Responding Yes (%) |
|---|------------------------|---------------------------|
| Intermittent use of an assistive device (ankle-foot orthotic device or AFO, cane, walker, etc.) | 237 | 25.9 |
| Dependent on assistive device | 225 | 24.6 |
| Wheelchair dependent | 243 | 26.6 |
| Not applicable | 2 | 0.2 |
| Climbing Stairs | 901 | |
| Normal | 13 | 1.4 |
| Slow with hesitation or increased effort; uses hand rail intermittently | 63 | 7.0 |
| Dependent on hand rail | 157 | 17.4 |
| Dependent on hand rail and additional support (cane or person) | 156 | 17.3 |
| Cannot climb stairs | 512 | 56.8 |
| Assistance in Daily Living | | |
| Done by you | | 58.4 |
| Done by your spouse, other family or friends | | 30.9 |
| Done by paid household help | | 4.1 |
| Done by paid health-care help | | 5.6 |
| Walking Ability | 792 | |
| More than a mile | 82 | 10.4 |
| ½ to 1 mile | 72 | 9.1 |
| ¼ to ½ mile | 87 | 11.0 |
| Less than a block | 524 | 66.2 |
| A city block or more | 143 | 18.1 |
| Transportation Modes Used | | |
| Self driven auto | 504 | 55.3 |
| Auto driven by other | 561 | 61.5 |
| Other (Train) | 28 | 3.1 |
| Other (Airplane) | 82 | 9.0 |
| Other (Public bus or subway) | 55 | 6.0 |
| Days Away from Home in Last Year | 909 | |
| Less than 7 days | 373 | 41.0 |
| At least 7 days but less than 30 days | 345 | 38.0 |
| At least 30 days but less than 90 days | 127 | 14.0 |

| Patient characteristic | Respondents (n) | Responding Yes (%) |
|--|------------------------|---------------------------|
| 90 days or more | 64 | 7.0 |
| Amount that IBM Interfered with Normal Work (including work outside the home and housework) | 864 | |
| Not at all | 20 | 2.3 |
| Slightly | 40 | 4.6 |
| Somewhat | 144 | 16.7 |
| Extremely | 356 | 41.2 |
| Considerably | 282 | 32.6 |
| Not applicable | 22 | 2.5 |
| Influence of IBM on Energy Levels | 911 | |
| Not at all | 23 | 2.5 |
| Scarcely | 39 | 4.3 |
| Some of the time | 216 | 23.7 |
| All of the time | 288 | 31.6 |
| Most of the time | 343 | 37.7 |
| Not applicable | 2 | 0.2 |
| Influence of IBM on Mood Towards Depression | 910 | |
| Not at all | 111 | 12.2 |
| Scarcely | 199 | 21.9 |
| Some of the time | 422 | 46.4 |
| All of the time | 53 | 5.8 |
| Most of the time | 125 | 13.7 |
| Not applicable | 0 | 0.0 |

TABLE S4. DIAGNOSIS AND CLINICAL DEMOGRAPHICS.

| Clinical characteristic | Respondents (n) | Responding Yes (%) |
|---|------------------------|---------------------------|
| Symptoms That Compelled Doctors Visit | | |
| Trouble swallowing | 211 | 23.0 |
| Impaired use of arms and legs | 489 | 53.4 |
| Weakness | 640 | 69.9 |
| Fatigue | 293 | 32.0 |
| Falls | 520 | 56.8 |
| Difficulty climbing stairs | 546 | 59.6 |
| Other | 187 | 20.4 |
| Time Span Between First Observed Symptoms and First Doctor's Diagnosis | 909 | |
| 1-3 months | 60 | 6.6 |
| 3-6 months | 84 | 9.2 |
| 6-12 months | 130 | 14.3 |
| 1-2 years | 207 | 22.8 |
| 2 or more years | 417 | 45.9 |
| Other | 11 | 1.2 |
| Nature of First Diagnosis | 914 | |
| IBM | 465 | 50.9 |
| Polymyositis | 172 | 18.8 |
| Arthritis | 39 | 4.3 |
| Do not know | 53 | 5.8 |
| Other | 185 | 20.2 |
| Physician Who Gave This Diagnosis | 911 | |
| Primary Care | 97 | 10.7 |
| Neurologist | 631 | 69.3 |
| Rheumatologist | 131 | 14.3 |
| Other | 52 | 5.7 |
| Physician First to Diagnose Disease as IBM | 916 | |
| Primary Care | 24 | 2.6 |
| Neurologist | 717 | 78.3 |
| Rheumatologist | 102 | 11.1 |
| Other | 73 | 8.0 |

| Clinical characteristic | Respondents (n) | Responding Yes (%) |
|---|------------------------|---------------------------|
| Biopsy Done at that Time? | 910 | |
| Yes | 826 | 90.8 |
| No | 81 | 8.9 |
| I don't know | 3 | 0.3 |
| Knowledge of Anyone Who Has Had a Remission from IBM | 914 | |
| Yes | 21 | 2.3 |
| No | 893 | 97.7 |