## 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
	Gamma 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
	U White
0(	
Q6.	Height: (Please fill in)
	feetinches
Q7.	Current weight: (Please fill in)
	nounds
	pounds

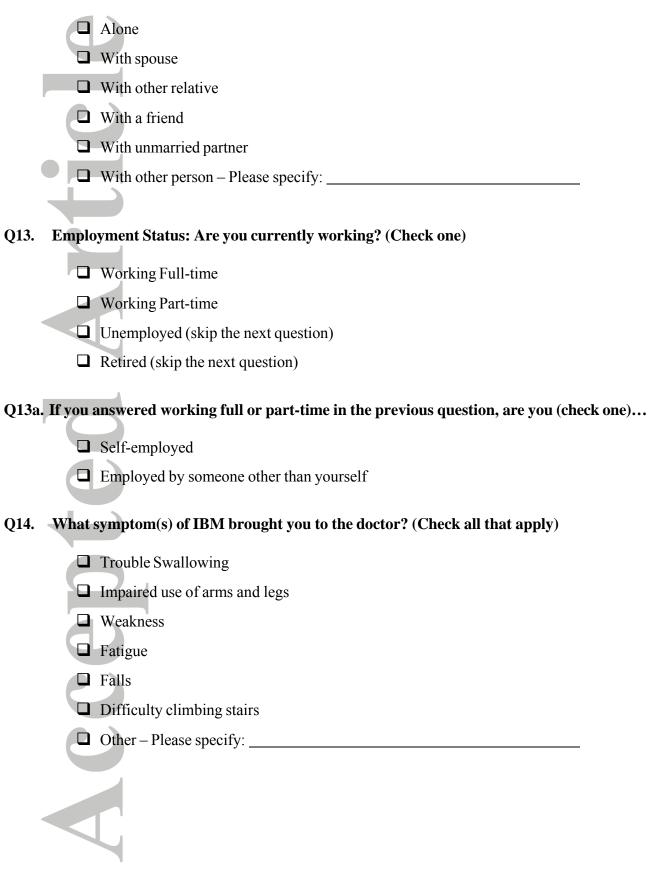
## Q8. Please check the highest educational level you finished: (Check one)

- 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
  - U 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: \_\_\_\_\_

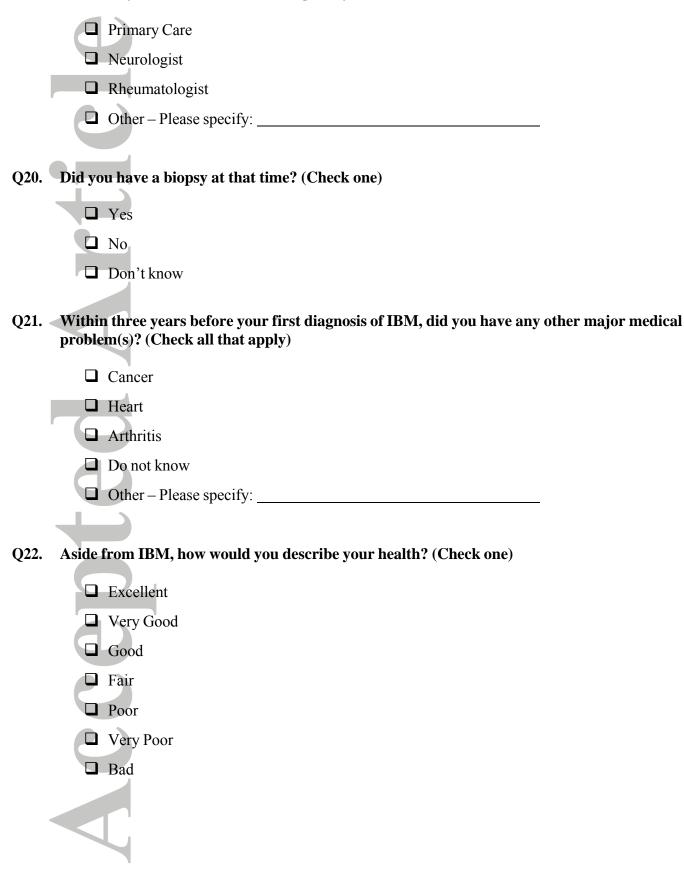


Q15. How long was the time between your first observed symptoms and your first doctor's diagnosis? (Check one)

	□ 1-3 Months
	$\Box$ 3-6 Months
	G-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)

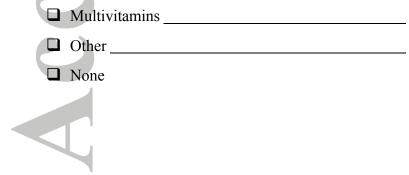
Months – Specify: \_\_\_\_\_ Years – Specify: \_\_\_\_\_

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



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

C Zero
• One
Two
More – Please specify number:
Q24. What Physician(s) do you see specifically concerning IBM? (Check all that apply)
C 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
D 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



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



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

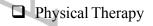
# Q26a. How many hours per week do you generally exercise, including physical therapy and all other exercises? (Please check one)

□ 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)



□ Swimming

# 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
- U 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?\_\_\_\_\_%

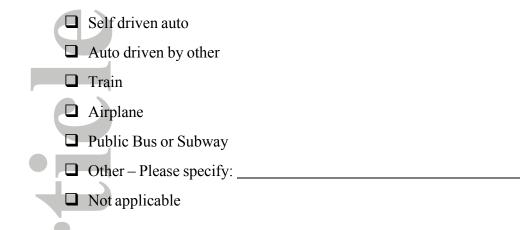
TOTAL OF ALL ANSWERS SHOULD EQUAL

<u>100%</u>

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

- □ More than a mile
- $\Box$  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)



#### 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?
  - YesNo

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:

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## 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?

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Patient characteristic	Respondents (n)	Responding Ye
		(/0)
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

## TABLE S2. GENERAL DEMOGRAPHICS

Patient characteristic	Respondents (n)	Responding Yes
	Respondents (II)	(%)
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
30-33	98	11.0

Patient characteristic	Respondents (n)	Responding Ye
	Respondents (II)	(%)
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
<b>Cutting Food and Handling Utensils</b>	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	200	22.4
needed		
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	204	22.4
devices		
Frequently requires assistance from caregiver	132	14.5
Unable	47	5.2

## TABLE S3. DAILY LIVING AND AMBULATION

Patient characteristic	Respondents (n)	Responding Yes
	Respondents (II)	(%)
	012	
Dressing	913	1.6.6
Normal	152	16.6
Independent but with increased effort of decreased efficiency	349	38.2
Independent but requires assistive devices or modified	116	12.7
techniques (Velcro snaps, shirts without buttons, etc.)	100	
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	323	35.4
chair, raised toilet seat, etc.)		
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)	35	3.8
but without use of arms		
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

Patient characteristic	Degnandants (n)	Responding Yes
	Respondents (n)	(%)
Intermittent use of an assistive device (ankle-foot orthotic	237	25.9
device or AFO, cane, walker, etc.)	201	
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	63	7.0
intermittently		
Dependent on hand rail	157	17.4
Dependent on hand rail and additional support (cane or	156	17.3
person)		
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
Valking Ability	792	
More than a mile	82	10.4
<sup>1</sup> / <sub>2</sub> to 1 mile	72	9.1
<sup>1</sup> /4 to <sup>1</sup> /2 mile	87	11.0
Less than a block	524	66.2
A city block or more	143	18.1
Fransportation 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	864	
work outside the home and housework)		
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

Not app

Clinical characteristic	Respondents (n)	Responding Yo
		(70)
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	909	
Doctor's Diagnosis		
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

## TABLE S4. DIAGNOSIS AND CLINICAL DEMOGRAPHICS.

Clinical characteristic	Respondents (n)	Responding Yes (%)
<b>Biopsy Done at that Time?</b>	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

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