

Participant (Subject) #: _____

UNDERSTANDING THE LIFESTYLE IMPACTS OF LYME DISEASE SURVEY FORM

Title of research project: Understanding the Impact of Emerging Infectious Diseases in Human Populations: the case for Lyme disease

SECTION A

1. What gender are you?
☐ Male ☐ Female
2. What is your age? _____
3. What state do you live in? _____
4. What county do you live in? _____
5. What kind of community do you live in?
☐ Urban/city ☐ Sub-urban/large town ☐ Small town/village
☐ Rural/country ☐ Other (please specify): _____
6. What is your primary occupational environment?
☐ Farm/agriculture ☐ Office Building ☐ Work from home
☐ Factory work ☐ School ☐ Forestry/park service
☐ Hospital/healthcare ☐ Machine shop/mechanic ☐ Construction
☐ Animal/Veterinary clinic ☐ Quarry/gas drilling
☐ Other (please specify): _____
7. How do you describe your ethnicity?
☐ White (Caucasian) ☐ African American ☐ Australasian
☐ Asian ☐ African ☐ Hawaiian/Pacific Islander
☐ Latino ☐ Other (please specify): _____
8. Do you have any household pets? (i.e., pets that live INSIDE your home?)
☐ Yes ☐ No
9. If you own a household pet, what pets do you own? Check all that apply
☐ Not applicable ☐ Dog(s) ☐ Cat(s)
☐ Other (please specify): _____

Participant (Subject) #: _____

10. How often do you exercise?

- ☐ Never ☐ Less than once per month ☐ 1-3 times per month
☐ 1-3 times per week ☐ 4-6 times per week ☐ Everyday

11. How often do you engage in social activities (i.e. go out with friends, etc.)?

- ☐ Never ☐ Less than once per month ☐ 1-3 times per month
☐ 1-3 times per week ☐ 4-6 times per week ☐ Everyday

12. How many meals do you typically eat per day?

- ☐ 1 meal ☐ 2 meals ☐ 3 meals
☐ 4 meals ☐ 5 meals ☐ 6+ meals

13. How many hours do you typically sleep in a 24 hour period?

- ☐ 1-3 ☐ 4-6 ☐ 7-9
☐ 10-12 ☐ 13-15 ☐ 16+

14. How often do you feel tired or lethargic after a typical night sleep?

- ☐ Never ☐ Rarely ☐ Sometimes
☐ Often ☐ Always

15. How would you categorize your overall health?

- ☐ Very Poor ☐ Poor ☐ Neither good nor poor
☐ Good ☐ Very good

16. How would you assess your overall health compared to that of others of your own age?

- ☐ Much worse ☐ Slightly worse ☐ Neither better nor worse
☐ Slightly better ☐ Much better

17. How often do you feel fearful?

- | | | | | | | |
|--------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-------|
| | 1 | 2 | 3 | 4 | 5 | |
| Always | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | Never |

18. How often do you feel angry?

- | | | | | | | |
|--------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-------|
| | 1 | 2 | 3 | 4 | 5 | |
| Always | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | Never |

Participant (Subject) #: _____

19. How often do you feel sad?

Always ¹
☐ ²
☐ ³
☐ ⁴
☐ ⁵
☐ Never

20. How often do you feel happy?

Always ¹
☐ ²
☐ ³
☐ ⁴
☐ ⁵
☐ Never

21. How often do you feel anticipation?

Always ¹
☐ ²
☐ ³
☐ ⁴
☐ ⁵
☐ Never

22. On average, how many times per year do you visit the doctor (primary care physician)?

☐ 0 ☐ 1-2 ☐ 3-5 ☐ 6-8
☐ 9-11 ☐ 12-14 ☐ 15+

23. Do you know someone (other than yourself) that has been diagnosed with Lyme disease (by a physician)?

☐ Yes ☐ No

24. If you know someone that's been diagnosed with Lyme disease, what is their relation to you? Check all that apply.

☐ Not applicable ☐ Spouse ☐ Child
☐ Sibling ☐ Parent ☐ Relative (not immediate)
☐ Friend ☐ Acquaintance
☐ Other (please specify): _____

25. How often do you wear bug spray (containing DEET) when you are outside (i.e. gardening, hiking, walking, etc.)?

☐ Never ☐ Rarely ☐ Sometimes
☐ Often ☐ Always

26. How often do you check yourself for ticks after being outside (i.e. gardening, hiking, walking, etc.)?

☐ Never ☐ Rarely ☐ Sometimes
☐ Often ☐ Always

Participant (Subject) #: _____

27. Have you ever been diagnosed with Lyme disease by a physician?

☐ Yes ☐ No

*(If NO, please continue to **SECTION C**. If YES, please continue to **SECTION B**)*

SECTION B

28. When were you diagnosed with Lyme disease (for the first time if you've had multiple diagnoses) (year; i.e. 2003)? _____

29. If you have been diagnosed with Lyme, were you treated by a physician?

☐ Yes ☐ No

30. Did your symptoms clear after initial treatment?

☐ Yes ☐ No

31. If your symptoms did NOT clear after initial treatment, were you treated again?

☐ Not applicable ☐ Yes ☐ No

32. Approximately how long did your symptoms last from the time you were first diagnosed with Lyme disease?

☐ 1-2 weeks ☐ 3-4 weeks ☐ 2-4 months ☐ 4-6 months

☐ 6-8 months ☐ 8-10 months ☐ 10-12 months ☐ 1-2 years

☐ 2-5 years ☐ 5+ years ☐ My symptoms are still occurring

33. What symptoms did you experience? Check all that apply.

☐ Erythema migrans rash ☐ Fever ☐ Knee joint pain

☐ Hip joint pain ☐ Ankle joint pain ☐ Elbow joint pain

☐ Shoulder joint pain ☐ Wrist joint pain ☐ Other joint pain

☐ Neck pain ☐ Muscle weakness ☐ Leg muscle cramps

☐ Back muscle cramps ☐ Arm muscle cramps ☐ Other muscle cramps

☐ Facial tingling ☐ Facial paralysis ☐ Impaired memory

☐ Sore throat ☐ Unusual hair loss ☐ Difficulty comprehending

☐ Absent mindedness ☐ Confusion ☐ Dizziness

☐ Light headedness ☐ Misspeaking ☐ Anxiousness

☐ Unusual fatigue ☐ Mood swings ☐ Nausea

Participant (Subject) #: _____

☐ Diarrhea

☐ Heart burn

☐ Other (please specify): _____

34. Were you ever diagnosed with Post-Treatment Lyme Disease Syndrome by a physician?

☐ Yes ☐ No

35. Can you recall ever being bitten by a tick?

☐ Yes ☐ No

36. How often did you exercise **BEFORE** being diagnosed with Lyme disease?

☐ Never ☐ Less than once per month ☐ 1-3 times per month

☐ 1-4 times per week ☐ 4-6 times per week ☐ Everyday

37. How often do you exercise now, **AFTER** being diagnosed with Lyme disease?

☐ Never ☐ Less than once per month ☐ 1-3 times per month

☐ 1-3 times per week ☐ 4-6 times per week ☐ Everyday

38. How often did you engage in social activities (i.e. go out with friends, etc.) **BEFORE** being diagnosed with Lyme disease?

☐ Never ☐ Less than once per month ☐ 1-3 times per month

☐ 1-3 times per week ☐ 4-6 times per week ☐ Everyday

39. How often do you engage in social activities (i.e. go out with friends, etc.) now, **AFTER** being diagnosed with Lyme disease?

☐ Never ☐ Less than once per month ☐ 1-3 times per month

☐ 1-3 times per week ☐ 4-6 times per week ☐ Everyday

40. How many meals did you typically eat per day **BEFORE** being diagnosed with Lyme disease?

☐ 1 meal ☐ 2 meals ☐ 3 meals

☐ 4 meals ☐ 5 meals ☐ 6+ meals

41. How many meals do you typically eat per day now, **AFTER** being diagnosed with Lyme disease?

☐ 1 meal ☐ 2 meals ☐ 3 meals

☐ 4 meals ☐ 5 meals ☐ 6+ meals

Participant (Subject) #: _____

42. How many hours did you typically sleep in a 24 hour period **BEFORE** being diagnosed with Lyme disease?

☐ 1-3

☐ 4-6

☐ 7-9

☐ 10-12

☐ 13-15

☐ 16+

43. How many hours do you typically sleep in a 24 hour period now, **AFTER** being diagnosed with Lyme disease?

☐ 1-3

☐ 4-6

☐ 7-9

☐ 10-12

☐ 13-15

☐ 16+

44. How often did you feel tired or lethargic after a typical night sleep **BEFORE** being diagnosed with Lyme disease?

☐ Never

☐ Rarely

☐ Sometimes

☐ Often

☐ Always

45. How often do you feel tired or lethargic after a typical night sleep now, **AFTER** being diagnosed with Lyme disease?

☐ Never

☐ Rarely

☐ Sometimes

☐ Often

☐ Always

46. How would you categorize your overall health **BEFORE** being diagnosed with Lyme disease?

☐ Very Poor

☐ Poor

☐ Neither good nor poor

☐ Good

☐ Very good

47. How would you categorize your overall health **AFTER** being diagnosed with Lyme disease?

☐ Very Poor

☐ Poor

☐ Neither good nor poor

☐ Good

☐ Very good

48. How would you assess your overall health compared to that of others of your own age **BEFORE** being diagnosed with Lyme disease?

☐ Much worse

☐ Slightly worse

☐ Neither better nor worse

☐ Slightly better

☐ Much better

49. How would you assess your overall health compared to that of others of your own age **AFTER** being diagnosed with Lyme disease?

Participant (Subject) #: _____

☐ Much worse

☐ Slightly worse

☐ Neither better nor worse

☐ Slightly better

☐ Much better

50. How often did you feel fearful **BEFORE** being diagnosed with Lyme disease?

| | | | | | | |
|--------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-------|
| | 1 | 2 | 3 | 4 | 5 | |
| Always | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | Never |

51. How often do you feel fearful now, **AFTER** being diagnosed with Lyme disease?

| | | | | | | |
|--------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-------|
| | 1 | 2 | 3 | 4 | 5 | |
| Always | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | Never |

52. How often did you feel angry **BEFORE** being diagnosed with Lyme disease?

| | | | | | | |
|--------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-------|
| | 1 | 2 | 3 | 4 | 5 | |
| Always | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | Never |

53. How often do you feel angry now, **AFTER** being diagnosed with Lyme disease?

| | | | | | | |
|--------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-------|
| | 1 | 2 | 3 | 4 | 5 | |
| Always | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | Never |

54. How often did you feel sad **BEFORE** being diagnosed with Lyme disease?

| | | | | | | |
|--------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-------|
| | 1 | 2 | 3 | 4 | 5 | |
| Always | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | Never |

55. How often do you feel sad now, **AFTER** being diagnosed with Lyme disease?

| | | | | | | |
|--------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-------|
| | 1 | 2 | 3 | 4 | 5 | |
| Always | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | Never |

56. How often did you feel happy **BEFORE** being diagnosed with Lyme disease?

| | | | | | | |
|--------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-------|
| | 1 | 2 | 3 | 4 | 5 | |
| Always | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | Never |

57. How often do you feel happy now, **AFTER** being diagnosed with Lyme disease?

| | | | | | | |
|--------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-------|
| | 1 | 2 | 3 | 4 | 5 | |
| Always | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | Never |

58. How often did you feel anticipation **BEFORE** being diagnosed with Lyme disease?

| | | | | | | |
|--------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-------|
| | 1 | 2 | 3 | 4 | 5 | |
| Always | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | Never |

59. How often do you feel anticipation now, **AFTER** being diagnosed with Lyme disease?

| | | | | |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|

Participant (Subject) #: _____

Always ☐ ☐ ☐ ☐ ☐ Never

60. On average, how many times per year did you visit the doctor (primary care physician or specialist) **BEFORE** being diagnosed with Lyme disease?

☐ 0 ☐ 1-2 ☐ 3-5 ☐ 6-8

☐ 9-11 ☐ 12-14 ☐ 15+

61. On average, how many times per year do you visit the doctor (primary care physician or specialist) now, **AFTER** being diagnosed with Lyme disease?

☐ 0 ☐ 1-2 ☐ 3-5 ☐ 6-8

☐ 9-11 ☐ 12-14 ☐ 15+

62. How often did you wear bug spray (containing DEET) when you are outside (i.e. gardening, hiking, walking, etc.) **BEFORE** being diagnosed with Lyme disease?

☐ Never ☐ Rarely ☐ Sometimes

☐ Often ☐ Always

63. How often do you wear bug spray (containing DEET) when you are outside (i.e. gardening, hiking, walking, etc.) **AFTER** being diagnosed with Lyme disease?

☐ Never ☐ Rarely ☐ Sometimes

☐ Often ☐ Always

64. How often did you check yourself for ticks after being outside (i.e. gardening, hiking, walking, etc.) **BEFORE** being diagnosed with Lyme disease?

☐ Never ☐ Rarely ☐ Sometimes

☐ Often ☐ Always

65. How often do you check yourself for ticks after being outside (i.e. gardening, hiking, walking, etc.) **AFTER** being diagnosed with Lyme disease?

☐ Never ☐ Rarely ☐ Sometimes

☐ Often ☐ Always

SECTION C

66. Would you like to receive an email update when data analyses are complete?

a. Yes (please provide email address): _____

b. No

Thank you for participating in this survey. The information you provide will assist in gaining a better understanding of Lyme disease and the impact it has on human health.

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Should you have any questions, please do not hesitate to contact Amanda Roome at aroome1@binghamton.edu.