Form Approved
OMB No. 0920-New
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Men Living with Muscular Dystrophy Survey

INTRODUCTION

This survey asks about you and your experiences as a person diagnosed with muscular dystrophy. We will ask you about you and your household, your experience with COVID-19 and vaccination, chronic pain and fatigue related to your muscular dystrophy, and your experiences with family planning and family building.

The survey should take no more than 15 minutes to complete. You may skip any questions you do not wish to answer. We will not publish any information that can be linked to you or your household.

This survey is conducted by the Centers for Disease Control and Prevention and the members of the Muscular Dystrophy Surveillance, Research and Tracking Network (MD STAR*net*). Additional information on MD STAR*net* can be found at the following links:
https://www.cdc.gov/ncbddd/musculardystrophy/research.html
and https://mdstarnet.org/

If you have any questions about this survey, you can call our study coordinator at **<1 (XXX) XXX-XXXX>.**

If you have questions about your rights as a research participant, please contact the **<grantee institution office of research>** at **<1 (XXX)XXX-XXXX>**.

Thank you for helping improve care for people like you living with muscular dystrophy!

INSTRUCTIONS

Mark your answer by completely filling in the circle or marking an X in the box to the left of your answer.

☒ A doctor or health care provider
☐ A family member

Use a black or blue pen, if available.

The first set of questions are about you and your household.

START HERE

1.
1.

What is your ethnicity?

☐ Hispanic or Latino
☐ Not Hispanic or Latino

2. What race do you identify with?
Please check all that apply.

☐ American Indian/Alaskan Native
☐ Asian
☐ Black or African American
☐ Native Hawaiian or Pacific Islander
☐ White
☐ Other

3. Are you currently attending a school or college?

☐ Yes
☐ No
☐ I don't know
☐ I prefer not to answer

4. What is the highest level of education you completed?

☐ Elementary school (grades 1 through 8)
☐ Some high school (grades 9 through 11)
☐ Graduated high school (grade 12)
☐ Some college or technical school
☐ Graduated college or technical school
☐ Graduate school
☐ I don't know
☐ I prefer not to answer

5. Do you own or rent your home?

☐ Own
☐ Rent
☐ Other arrangement
☐ I don't know
☐ I prefer not to answer

6. What is your current employment status?

☐ Employed for wages→ ***Go to Next Question***
☐ Self-employed→ ***Go to Next Question***
☐ Out of work for a year or more
☐ Out of work for less than a year
☐ Homemaker
☐ Student
☐ Retired
☐ Unable to work
☐ Other, please specify: _____
☐ I don't know
☐ I prefer not to answer

7. If employed, how many hours per week are you working?

☐ Less than 20 hours per week
☐ 20-40 hours per week
☐ More than 40 hours per week
☐ I don't know
☐ I prefer not to answer

8. During the last 12 months, what was your yearly total household income before taxes?

☐ $40 to $9,999
☐ $10,000 to $24,999
☐ $25,000 to 49,999
☐ $50,000 to 74,999
☐ $75,000 to 99,999
☐ $100,000 to 149,999
☐ $150,000 and greater
☐ I don't know
I prefer not to answer

The following questions are about COVID-19 and influenza.

9. To your knowledge, have you had COVID-19?
   - ☐ Yes
   - ☐ No → ***Go to question 13***
   - ☐ I don't know → ***Go to 13***
   - ☐ I prefer not to answer → ***Go to 13***

10. Was your infection confirmed by a test?
   - ☐ Yes, confirmed by test
   - ☐ No, not confirmed by test
   - ☐ I don't know
   - ☐ I prefer not to answer

11. Describe the level of care you received.
   - ☐ Did not seek medical care
   - ☐ Received medical care but was not hospitalized
   - ☐ Was hospitalized
   - ☐ I don't know
   - ☐ I prefer not to answer

12. How would you characterize your symptoms?
   - ☐ No symptoms
   - ☐ Mild (e.g., low-grade fever, cough, shortness of breath)
   - ☐ Moderate (e.g., moderate difficulty breathing, body aches, fatigue)
   - ☐ Severe (e.g., severe difficulty breathing, persistent pain, inability to stay awake)
   - ☐ I don't know
   - ☐ I prefer not to answer

13. Have you received a COVID-19 vaccine?
   - ☐ Yes → ***Go to question 15***
   - ☐ No
   - ☐ I don't know → ***Go to 15***
   - ☐ I prefer not to answer → ***Go to 15***

14. What are the reasons you have not received a COVID-19 vaccine? (Check all that apply)
   - ☐ I would like to get it but have not been able to
   - ☐ I am worried about the side effects of the vaccine
   - ☐ I do not like vaccines or needles
   - ☐ I am not worried about getting COVID-19
   - ☐ I already had COVID-19
   - ☐ I have a medical condition that prevents me from getting the vaccine
   - ☐ I do not think the vaccine is effective
   - ☐ I just don't want the vaccine
   - ☐ Other, specify:_____
   - ☐ I don't know
   - ☐ I prefer not to answer

15. Have you ever received a flu vaccine?
   - ☐ Yes
   - ☐ No → ***Go to question 17***
   - ☐ I don't know → ***Go to question 18***
   - ☐ I prefer not to answer → ***Go to 18***

16. Did you receive the flu vaccine any time in the last 12 months?
   - ☐ Yes → ***Go to question 18***
   - ☐ No
   - ☐ I don't know → ***Go to 18***
   - ☐ I prefer not to answer → ***Go to 18***

17. What are the reasons you have not received the flu vaccine during the past 12 months? (Check all that apply)
   - ☐ I would like to get it but have not been able to
   - ☐ I am worried about the side effects of the vaccine
   - ☐ I do not like vaccines or needles
   - ☐ I am not worried about getting the flu
   - ☐ I already had the flu
   - ☐ I have a medical condition that prevents me from getting the vaccine
   - ☐ I do not think the vaccine is effective
   - ☐ I just don't want the vaccine
   - ☐ Other, specify: _____
   - ☐ I don't know
   - ☐ I prefer not to answer

The next set of questions ask about your experience with chronic pain and fatigue *related to your muscular dystrophy*.

18. In the past **30 days**, how many days have you experienced pain related to your muscular dystrophy in any part of your body?
   - ☐ _____ number of days
   - ☐ I cannot recall having muscular dystrophy-related pain in the last 30 days → ***Go to question 52***
   - ☐ I prefer not to answer → ***Go to 52***

19. Is your pain managed by medication or other methods?
☐ Yes
☐ No
☐ I don't know
☐ I prefer not to answer

20. What time of day is your pain the worst? ***Check all that apply***.
☐ Morning
☐ Afternoon
☐ Evening/night
☐ I don't know
☐ I prefer not to answer

21. Where in your body do you typically have pain?
Check all that apply.
☐ Head
☐ Neck
☐ Shoulders
☐ Arms
☐ Back
☐ Chest
☐ Stomach
☐ Hips
☐ Legs
☐ Feet
☐ Other, specify: _____
☐ I don't know
☐ I prefer not to answer

The next questions are about how you have managed your pain in the past 30 days.

22. Do you use over-the-counter/non-prescription pain medications such as aspirin, ibuprofen, or acetaminophen to manage the pain related to your muscular dystrophy?
☐ Yes
☐ No → ***Go to question 25***
☐ I don't know→ ***Go to 25***
☐ I prefer not to answer→ ***Go to 25***

23. How often do you use any combination of this type of medication to manage your pain?
☐ Every day
☐ 2-6 days per week
☐ Once a week
☐ Once a month
☐ Not in the last month
☐ I don't know
☐ I prefer not to answer

24. How helpful are any combination of these medications in managing your pain?
☐ Completely relieve the pain
☐ Reduce pain so I can manage my normal activities
☐ Provide some relief but not enough that I can resume normal activities
☐ Provide little or no pain relief
☐ I don't know
☐ I prefer not to answer

25. Do you use prescription opioid pain medications – such as Percocet (oxycodone), Vicodin (hydrocodone), or Ultram (tramadol) – to manage the pain related to your muscular dystrophy?
☐ Yes
☐ No → ***Go to question 28***
☐ I don't know→ ***Go to 28***
☐ I prefer not to answer → ***Go to 28***

26. How often do you use any combination of this type of medication to manage your pain?
    - ☐ Every day
    - ☐ 2-6 days per week
    - ☐ Once a week
    - ☐ Once a month
    - ☐ Not in the last month
    - ☐ I don't know
    - ☐ I prefer not to answer

27. How helpful are any combination of these medications in managing your pain?
    - ☐ Completely relieve the pain
    - ☐ Reduce pain so I can manage my normal activities
    - ☐ Provide some relief but not enough that I can resume normal activities
    - ☐ Provide little or no pain relief
    - ☐ I don't know
    - ☐ I prefer not to answer

28. Do you use cannabidiol (CBD) or any other marijuana-based treatment products to manage the pain related to your muscular dystrophy?
    - ☐ Yes
    - ☐ No → ***Go to question 31***
    - ☐ I don't know→ ***Go to 31***
    - ☐ I prefer not to answer → ***Go to 31***

29. How frequently do you use any combination of CBD or marijuana-based treatment products to manage your pain?
    - ☐ Every day
    - ☐ 2-6 days per week
    - ☐ Once a week
    - ☐ Once a month
    - ☐ Not in the last month
    - ☐ I don't know
    - ☐ I prefer not to answer

30. How helpful are any combination of CBD or marijuana-based treatment products in managing your pain?
    - ☐ Completely relieve the pain
    - ☐ Reduce pain so I can manage my normal activities
    - ☐ Provide some relief but not enough that I can resume normal activities
    - ☐ Provide little or no pain relief
    - ☐ I don't know
    - ☐ I prefer not to answer

31. Do you use alternative medications – such as herbal supplements – to manage the pain related to your muscular dystrophy?
    - ☐ Yes
    - ☐ No → ***Go to question 34***
    - ☐ I don't know → ***Go to 34***
    - ☐ I prefer not to answer → ***Go to 34***

32. How frequently do you use any combination of this type of medication to manage your pain?
    - ☐ Every day
    - ☐ 2-6 days per week
    - ☐ Once a week
    - ☐ Once a month
    - ☐ Not in the last month
    - ☐ I don't know
    - ☐ I prefer not to answer

33. How helpful are any combination of these medications in managing your pain?
    - ☐ Completely relieve the pain
    - ☐ Reduce pain so I can manage my normal activities
    - ☐ Provide some relief but not enough that I can resume normal activities
    - ☐ Provide little or no pain relief
    - ☐ I don't know
    - ☐ I prefer not to answer

34. Do you use nonpharmacological methods such as biofeedback, physical therapy, behavioral modifications, better sleep practices, better hygiene practices, or diet to manage the pain related to your muscular dystrophy?
☐ Yes
☐ No → ***Go to question 37***
☐ I don't know→ ***Go to 37***
☐ I prefer not to answer→ ***Go to 37***

35. How frequently do you use any combination of these methods to manage your pain?
☐ Every day
☐ 2-6 days per week
☐ Once a week
☐ Once a month
☐ Not in the last month
☐ I don't know
☐ I prefer not to answer

36. How helpful are any combinations of these methods in managing your pain?
☐ Completely relieve the pain
☐ Reduce pain so I can manage my normal activities
☐ Provide some relief but not enough that I can resume normal activities
☐ Provide little or no pain relief
☐ I don't know
☐ I prefer not to answer

37. Do you use any other method or therapy to manage your pain?
☐ Yes
☐ No → ***Go to question 41***
☐ I don't know→ ***Go to 41***
☐ I prefer not to answer→ ***Go to 41***

38. What other methods or therapies do you use?

39.
39.
39.
39.
39.
39.
39.
39.

How frequently do you use any combination of these other methods to manage your pain?
☐ Every day
☐ 2-6 days per week
☐ Once a week
☐ Once a month
☐ Not in the last month
☐ I don't know
☐ I prefer not to answer

40. How helpful are any combination of these other methods in managing your pain?
☐ Completely relieve the pain
☐ Reduce pain so I can manage my normal activities
☐ Provide some relief but not enough that I can resume normal activities
☐ Provide little or no pain relief
☐ I don't know
☐ I prefer not to answer

The next questions ask about the intensity of your pain. For each item, please ***mark the option*** that ***best*** describes the intensity of your pain during the indicated time period.

41. **In the past 7 days**, how intense was your pain at its worst?
☐ No pain
☐ Mild
☐ Moderate
☐ Severe
☐ Very severe
☐ I don't know
☐ I prefer not to answer

42. **In the past 7 days,** how intense was your **average** pain?
☐ No pain
☐ Mild
☐ Moderate
☐ Severe
☐ Very severe
☐ I don't know
☐ I prefer not to answer

43. What is your level of pain right now?
- ☐ No pain
- ☐ Mild
- ☐ Moderate
- ☐ Severe
- ☐ Very severe
- ☐ I don't know
- ☐ I prefer not to answer

The next questions are about the impact of pain on your activities. For each item, please *mark the option* that *best* describes how often the impact of pain occurred in the past 7 days.

44. **In the past 7 days,** how much did pain interfere with your day to day activities?
- ☐ Not at all
- ☐ A little bit
- ☐ Somewhat
- ☐ Quite a bit
- ☐ Very much
- ☐ I don't know
- ☐ I prefer not to answer

45. **In the past 7 days,** how much did pain interfere with work around the home?
- ☐ Not at all
- ☐ A little bit
- ☐ Somewhat
- ☐ Quite a bit
- ☐ Very much
- ☐ I don't know
- ☐ I prefer not to answer

46. **In the past 7 days,** how much did pain interfere with your ability to participate in social activities?
- ☐ Not at all
- ☐ A little bit
- ☐ Somewhat
- ☐ Quite a bit
- ☐ Very much
- ☐ I don't know
- ☐ I prefer not to answer

47. **In the past 7 days,** how much did pain interfere with your household chores?
- ☐ Not at all
- ☐ A little bit
- ☐ Somewhat
- ☐ Quite a bit
- ☐ Very much
- ☐ I don't know
- ☐ I prefer not to answer

48. **In the past 7 days,** how much did pain interfere with the things you usually do for fun?
- ☐ Not at all
- ☐ A little bit
- ☐ Somewhat
- ☐ Quite a bit
- ☐ Very much
- ☐ I don't know
- ☐ I prefer not to answer

49. **In the past 7 days,** how much did pain interfere with your enjoyment of social activities?
- ☐ Not at all
- ☐ A little bit
- ☐ Somewhat
- ☐ Quite a bit
- ☐ Very much
- ☐ I don't know
- ☐ I prefer not to answer

50. **In the past 7 days,** how much did pain interfere with your enjoyment of life?
- ☐ Not at all
- ☐ A little bit
- ☐ Somewhat
- ☐ Quite a bit
- ☐ Very much
- ☐ I don't know
- ☐ I prefer not to answer

51. **In the past 7 days,** how much did pain interfere with your family life?
- ☐ Not at all
- ☐ A little bit
- ☐ Somewhat
- ☐ Quite a bit
- ☐ Very much
- ☐ I don't know
- ☐ I prefer not to answer

The next questions are about how tired you felt during the past week and how feeling tired impacted your daily activities. In the past 7 days, how often was each of the following statements true? Please respond to each statement by marking the best answer.

52. I felt exhausted.
- ☐ Never
- ☐ Rarely
- ☐ Sometimes
- ☐ Often
- ☐ Always
- ☐ I don't know
- ☐ I prefer not to answer

53. I felt like I had no energy.
- ☐ Never
- ☐ Rarely
- ☐ Sometimes
- ☐ Often
- ☐ Always
- ☐ I don't know
- ☐ I prefer not to answer

54. I felt fatigued.
- ☐ Never
- ☐ Rarely
- ☐ Sometimes
- ☐ Often
- ☐ Always
- ☐ I don't know
- ☐ I prefer not to answer

55. I was too tired to do my household chores.
- ☐ Never
- ☐ Rarely
- ☐ Sometimes
- ☐ Often
- ☐ Always
- ☐ I don't know
- ☐ I prefer not to answer

56. I was too tired to leave the house.
- ☐ Never
- ☐ Rarely
- ☐ Sometimes
- ☐ Often
- ☐ Always
- ☐ I don't know
- ☐ I prefer not to answer

57. I was frustrated by being too tired to do the things I wanted to do.
- ☐ Never
- ☐ Rarely
- ☐ Sometimes
- ☐ Often
- ☐ Always
- ☐ I don't know
- ☐ I prefer not to answer

58. I felt tired.
- ☐ Never
- ☐ Rarely
- ☐ Sometimes
- ☐ Often
- ☐ Always
- ☐ I don't know
- ☐ I prefer not to answer

59. I had to limit my social activity because I was tired.
- ☐ Never
- ☐ Rarely
- ☐ Sometimes
- ☐ Often
- ☐ Always
- ☐ I don't know
- ☐ I prefer not to answer

If your response to all of the statements 52-59 was 'Never' or 'Rarely', please go to question 61.

60. How have you managed your fatigue in the past 7 days? ***Please check all that apply.***
☐ Stimulants
☐ Exercise
☐ Coffee and/or other caffeine containing beverages
☐ Prescription medications
☐ Non-prescription medications
☐ Dietary Supplements
☐ Sleep
☐ Herbal remedies
☐ Other, specify _____
☐ I don't know
☐ I prefer not to answer

61. Please tell us anything else about your experience with pain or fatigue.

The next questions are about your experience family planning.

62. At what age were you diagnosed with muscular dystrophy?
_____
☐ I don't know
☐ I prefer not to answer

63. Have you ever talked with a genetic counselor or other medical provider about the chance for your children or other family members to have muscular dystrophy?
☐ Yes
☐ No → ***Go to question 66***
☐ I don't know→ ***Go to 66***
☐ I prefer not to answer→ ***Go to 66***

64. When did you talk with the genetic counselor or medical provider?
☐ Before considering or having children
☐ During one of my partner's pregnancies
☐ Between my partner's pregnancies
☐ After I was done having children → ***Go to question 66***
☐ I don't remember/I don't know → ***Go to 66***
☐ I prefer not to answer → ***Go to 66***

65. How did speaking with this person affect your decision to have (more) children?
☐ It did not/will not affect my decision to have children
☐ I decided not to have my own children
☐ I decided to adopt
☐ I decided to see a medical provider who could help me have children without muscular dystrophy
☐ Other, specify: _____
_____
☐ I don't know
☐ I prefer not to answer

66. Some men are not physically able to father children. As far as you know, is it physically possible for you to biologically father a child now or in the future?
☐ Yes
☐ No
☐ I don't know
☐ I prefer not to answer

67. Have you ever had a vasectomy or any other operation that makes it impossible for you to father a child?
☐ Yes
☐ No
☐ I don't know
☐ I prefer not to answer

68. Were you ever told that you had any of the following male infertility problems? ***Check all that apply.***
☐ Low sperm count or no sperm
☐ Varicocele or varicose vein formation in scrotum.
☐ Genetic disorder that alters sperm production
☐ Low testosterone level

☐ Other, specify: _____
_____

☐ None of the above
☐ I don't know
☐ I prefer not to answer

69. As far as you know, how many times have you ever made someone pregnant?
Please include pregnancies that ended in live birth, pregnancies that ended in miscarriage, stillbirth, or abortion, and pregnancies that are ongoing.

☐ Number of times _____
☐ I have never made someone pregnant → ***Go to question 74***
☐ I don't know → ***Go to question 74***
☐ I prefer not to answer → ***Go to question 74***

70. How many of these pregnancies ended with a live birth?

☐ Number of pregnancies _____
☐ I don't know
☐ I prefer not to answer

71. How many pregnancies ended in miscarriage? A miscarriage is a pregnancy that ends before 20 weeks gestation.

☐ Number of pregnancies ended in miscarriage _____
☐ I don't know
☐ I prefer not to answer

72. How many pregnancies ended in stillbirth? A stillbirth is the birth of an infant that was alive through the first 20 weeks of pregnancy but died before or during delivery.

☐ Number of pregnancies ended in stillbirth_____
☐ I don't know
☐ I prefer not to answer

73. Did you and your partner use any of the following for any pregnancy? ***Please check ALL that apply***.

☐ None
☐ Hormone therapy or medications
☐ In-vitro fertilization (IVF)
☐ Pre-implantation diagnosis. (Genetic testing of the embryo before implantation following IVF)
☐ Artificial insemination with your sperm
☐ Artificial insemination with donor sperm
☐ Drugs to improve ovulation
☐ Surgery to correct blocked tubes
☐ Treatment for varicocele
☐ Other types of medical help, specify

☐
☐
☐
☐
☐
☐
☐
☐
☐

I don't know
☐ I prefer not to answer

74. Please tell us anything else about your experience with family planning or fathering children?

75. Did anyone help you fill out this survey?

☐ Yes
☐ No → ***end***
☐ I prefer not to answer → ***end***

76. What is the relationship of the person who helped you fill out this survey?

_____

☐ I prefer not to answer → ***end***

This is the end of the survey. Thank you for taking the time to answer our questions. Your answers will help us to better understand the lives of people with muscular dystrophy and can inform decision makers who plan services to support people with muscular dystrophy and their families.