



## Women 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 20 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 STARnet). Additional information on MD STARnet 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!

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## 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.**

1. What is your ethnicity?

### START HERE

- 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

- 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**

**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

Participant ID: \_\_\_\_\_

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?

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

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

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. Have you ever been pregnant?

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

67. Did you ever have trouble getting pregnant or were unable to get pregnant?

- Yes
- No
- I have not tried to get pregnant
- I don't know
- I prefer not to answer

68. Were you ever told by a medical provider that you would not be able to get pregnant or might have a hard time getting pregnant due to your muscular dystrophy?

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

69. Did you ever decide not to become pregnant because it would be a risk to your own health?

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

**Next, we are going to ask some questions about your pregnancies.**

70. How many times have you been pregnant, including pregnancies that may have ended

in miscarriages, stillbirths, abortion, or a tubal or molar pregnancy?

- \_\_\_\_\_ times
- I don't know
- I prefer not to answer

71. In your **first** pregnancy, how many babies were you carrying?

- 1
- 2 (twins)
- 3 or more (triplets or more)
- I don't know
- I prefer not to answer

**If you have never been pregnant, skip to Q119.**

72. What was the outcome(s) of the pregnancy? **If you carried more than one baby, please check all that apply.**

- Baby was born alive at less than 37 weeks of pregnancy (early or preterm)
- Baby was born alive at 37 weeks or later (term)
- Miscarriage (fetal loss) before 20 weeks of pregnancy
- Stillbirth (fetal loss) at 20 weeks of pregnancy or later
- Abortion (pregnancy medically ended for any reason)
- I don't know
- I prefer not to answer

73. When did this pregnancy end?

\_\_ / \_\_\_\_ (mm/yyyy)

- I don't know
- I prefer not to answer

If you only had **one** pregnancy, **please go to question 86.**

74. In your **second** pregnancy, how many babies were you carrying?

- 1
- 2 (twins)
- 3 or more (triplets or more)
- I don't know
- I prefer not to answer

75. What was the outcome(s) of the pregnancy? **If you carried more than one baby, please check all that apply.**

- Baby was born alive at less than 37 weeks of pregnancy (early or preterm)
- Baby was born alive at 37 weeks or later (term)
- Miscarriage (fetal loss) before 20 weeks of pregnancy
- Stillbirth (fetal loss) at 20 weeks of pregnancy or later
- Abortion (pregnancy medically ended for any reason)
- I don't know
- I prefer not to answer

76. When did this pregnancy end?

\_\_ / \_\_\_\_ (mm/yyyy)

- I don't know
- I prefer not to answer

If you only had **two** pregnancies, **please go to question 86.**

77. In your **third** pregnancy, how many babies were you carrying?

- 1
- 2 (twins)
- 3 or more (triplets or more)
- I don't know
- I prefer not to answer

78. What was the outcome(s) of the pregnancy? **If you carried more than one baby, please check all that apply.**

- Baby was born alive at less than 37 weeks of pregnancy (early or preterm)
- Baby was born alive at 37 weeks or later (term)
- Miscarriage (fetal loss) before 20 weeks of pregnancy
- Stillbirth (fetal loss) at 20 weeks of pregnancy or later
- Abortion (pregnancy medically ended for any reason)
- I don't know
- I prefer not to answer

79. When did this pregnancy end?

\_\_ / \_\_\_\_ (mm/yyyy)

- I don't know
- I prefer not to answer

If you only had **three** pregnancies, **please go to question 86.**

80. In your **fourth** pregnancy, how many babies were you carrying?

- 1
- 2 (twins)
- 3 or more (triplets or more)
- I don't know
- I prefer not to answer

81. What was the outcome(s) of the pregnancy? **If you carried more than one baby, please check all that apply.**

- Baby was born alive at less than 37 weeks of pregnancy (early or preterm)
- Baby was born alive at 37 weeks or later (term)
- Miscarriage (fetal loss) before 20 weeks of pregnancy
- Stillbirth (fetal loss) at 20 weeks of pregnancy or later
- Abortion (pregnancy medically ended for any reason)
- I don't know
- I prefer not to answer

82. When did this pregnancy end?

- \_\_ / \_\_ (mm/yyyy)
- I don't know
  - I prefer not to answer

If you only had **four** pregnancies, **please go to question 86.**

83. In your **fifth** pregnancy, how many babies were you carrying?

- 1
- 2 (twins)
- 3 or more (triplets or more)
- I don't know
- I prefer not to answer

84. What was the outcome(s) of the pregnancy? **If you carried more than one baby, please check all that apply.**

- Baby was born alive at less than 37 weeks of pregnancy (early or preterm)
- Baby was born alive at 37 weeks or later (term)
- Miscarriage (fetal loss) before 20 weeks of pregnancy
- Stillbirth (fetal loss) at 20 weeks of pregnancy or later
- Abortion (pregnancy medically ended for any reason)
- I don't know
- I prefer not to answer

85. When did this pregnancy end?

- \_\_ / \_\_ (mm/yyyy)
- I don't know
  - I prefer not to answer

**The following questions are about the first time you were pregnant.**

86. How old were you when you became pregnant with your **first** pregnancy?

- \_\_ years
- I don't know
  - I prefer not to answer

87. Did you or your partner use any of the following assisted technologies to get pregnant with your **first** pregnancy? **Please check all that apply**

- No assistance needed
- Hormone therapy or medications
- In-vitro fertilization (IVF)
- Pre-implantation diagnosis. (Genetic testing of the embryo before implantation following IVF)
- Artificial insemination with your partner's sperm
- Artificial insemination with donor sperm
- Drugs to improve ovulation
- Surgery to correct blocked tubes
- Treatment for varicocele
- Other types of medical help
- I don't know

I prefer not to answer

88. Did you have any of the following problems with your **first** pregnancy? **Please check all that apply.**

- No problems
- Gestational Hypertension (high blood pressure that started during this pregnancy)
- Pre-eclampsia or eclampsia
- Significant bleeding with delivery
- Significant bleeding while pregnant
- Infection
- Gestational diabetes (diabetes that started during this pregnancy)
- Too much amniotic fluid
- Too little amniotic fluid
- Labor pains more than 3 weeks before my baby was due (preterm or early labor)
- Water broke more than 3 weeks before your baby was due (preterm premature rupture of membranes or PPRM)
- Bad reaction to the anesthetic used during delivery
- I don't know
- I prefer not to answer

**If your first pregnancy did not end in a live birth, please go to question 91.**

89. How was your **first** baby delivered?

- Unassisted vaginal delivery
- Assisted vaginal delivery (forceps or vacuum extraction)
- Planned cesarean section
- Unplanned cesarean section, including emergency C-section
- I don't know
- I prefer not to answer

90. Did your **first** baby have any of the following problems?

- Born too small (Low birth weight)
- Died before she/he was 1 month old
- Neither of these problems
- I don't know
- I prefer not to answer

Participant ID: \_\_\_\_\_

**The next questions are about how your muscular dystrophy symptoms changed during your first pregnancy.**

For each of the following symptoms of muscular dystrophy, please tell me how the symptom changed **during** your **first** pregnancy.

91. During your pregnancy, was your muscle weakness

- Worse
- Better
- About the same
- Did not have muscle weakness before or during pregnancy
- I don't know
- I prefer not to answer

92. During your pregnancy, was your muscle pain

- Worse
- Better
- About the same
- Did not have pain before or during pregnancy
- I don't know
- I prefer not to answer

93. During your pregnancy, were your muscle cramps

- Worse
- Better
- About the same
- Did not have muscle cramps before or during pregnancy
- I don't know
- I prefer not to answer

94. During your pregnancy, was any difficulty you had walking

- Worse
- Better
- About the same
- Did not have difficulty walking before or during pregnancy
- I don't know
- I prefer not to answer

95. During your pregnancy, did you need more help with daily activities?

- Yes
- No
- About the same
- Did not need help with daily activities before or during my pregnancy
- I don't know
- I prefer not to answer

**Now, please tell me how each of the following symptoms of muscular dystrophy changed after your first pregnancy ended compared to your symptoms during the pregnancy.**

96. After your pregnancy ended, was your muscle weakness
- Worse
  - Better
  - About the same
  - Did not have muscle weakness before, during or after pregnancy
  - I don't know
  - I prefer not to answer
97. After your pregnancy ended, was your muscle pain
- Worse
  - Better
  - About the same
  - Did not have pain before, during or after pregnancy
  - I don't know
  - I prefer not to answer
98. After your pregnancy ended, were your muscle cramps
- Worse
  - Better
  - About the same
  - Did not have muscle cramps before, during or after pregnancy
  - I don't know
  - I prefer not to answer
99. After your pregnancy ended, was any difficulty you had walking
- Worse
  - Better

- About the same
- Did not have difficulty walking before, during or after pregnancy
- I don't know
- I prefer not to answer

100. After your pregnancy ended, did you need more help with daily activities than you did during your pregnancy?

- Yes
- No
- About the same
- Did not need help with daily activities before, during or after my pregnancy
- I don't know
- I prefer not to answer

101. Did any symptoms related to muscular dystrophy in your **first** pregnancy affect your decision to have future pregnancies?

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

102. After your **first** pregnancy, did a doctor, nurse, or other health care worker tell you that you had depression?

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

If you only had **one** pregnancy, ***please go to question 119***

**The following questions are about the most recent or last time you were pregnant.**

103. How old were you when you became pregnant with your most recent pregnancy?

- \_\_\_\_\_ years
- I don't know
  - I prefer not to answer

104. Did you or your partner use any of the following assistive technologies to get pregnant with your most recent pregnancy?

**Please check ALL that apply.**

- No assistance needed
- Hormone therapy or medications
- In-vitro fertilization (IVF)
- Pre-implantation diagnosis. (Genetic testing of the embryo before implantation following IVF)
- Artificial insemination with your partner's sperm
- Artificial insemination with donor sperm
- Drugs to improve ovulation
- Surgery to correct blocked tubes
- Treatment for varicocele
- Other types of medical help
- I don't know
- I prefer not to answer

105. Did you have any of the following problems with your most recent pregnancy?

**Please check all that apply.**

- No problems
- Gestational Hypertension (high blood pressure that started during this pregnancy)
- Pre-eclampsia or eclampsia
- Significant bleeding with delivery
- Significant bleeding while pregnant
- Infection
- Gestational diabetes (diabetes that started during this pregnancy)
- Too much amniotic fluid
- Too little amniotic fluid
- Labor pains more than 3 weeks before my baby was due (preterm or early labor)
- Water broke more than 3 weeks before your baby was due (preterm premature rupture of membranes or PPRM)
- Bad reaction to the anesthetic used during delivery
- I don't know
- I prefer not to answer

**If your last pregnancy did not end in a live birth, please go to question 119.]**

106. Did your most recent baby have any of the following problems?

- Born too small (Low birth weight)
- Died before she/he was 1 month old
- Neither of these problems
- I don't know
- I prefer not to answer

107. How was your most recent baby delivered?

- Unassisted vaginal delivery
- Assisted vaginal delivery (forceps or vacuum extraction)
- Planned cesarean section
- Unplanned cesarean section, including emergency C-section
- I don't know
- I prefer not to answer

**The next questions are about if and how your muscular dystrophy symptoms changed during your last pregnancy.**

For each of the following symptoms, please tell me how the symptom changed during your **most recent** pregnancy compared to right **before your most recent** pregnancy.

108. During your pregnancy, was your muscle weakness

- Worse
- Better
- About the same
- Did not have muscle weakness before or during pregnancy
- I don't know
- I prefer not to answer

109. During your pregnancy, was your muscle pain

- Worse
- Better
- About the same
- Did not have pain before or during pregnancy
- I don't know



- I prefer not to answer
- 110. During your pregnancy, were your muscle cramps
  - Worse
  - Better
  - About the same
  - Did not have muscle cramps before or during pregnancy
  - I don't know
  - I prefer not to answer

- 111. During your pregnancy, was any difficulty you had walking
  - Worse
  - Better
  - About the same
  - Did not have difficulty walking before or during pregnancy
  - I don't know
  - I prefer not to answer

- 112. During your pregnancy, did you need more help with daily activities?
  - Yes
  - No
  - About the same
  - Did not need help with daily activities before or during my pregnancy
  - I don't know
  - I prefer not to answer

- 113. After your most recent pregnancy ended, was your muscle weakness
  - Worse
  - Better
  - About the same
  - Did not have muscle weakness before, during or after pregnancy
  - I don't know
  - I prefer not to answer

- 114. After your most recent pregnancy ended, was your muscle pain
  - Worse
  - Better
  - About the same
  - Did not have pain before, during or after pregnancy
  - I don't know
  - I prefer not to answer

115. After your most recent pregnancy

- ended, were your muscle cramps
  - Worse
  - Better
  - About the same
  - Did not have muscle cramps before, during or after pregnancy
  - I don't know
  - I prefer not to answer

Now, please tell me how each of the following symptoms changed after your **most recent pregnancy** ended compared to your symptoms during your **most recent pregnancy**.

Participant ID: \_\_\_\_\_

116. After your most recent pregnancy ended, was any difficulty you had walking

- Worse
- Better
- About the same
- Did not have difficulty walking before, during or after pregnancy
- I don't know
- I prefer not to answer

117. After your most recent pregnancy, did you need more help with daily activities than you did during your pregnancy?

- Yes
- No
- About the same
- Did not need help with daily activities before, during or after my pregnancy
- I don't know
- I prefer not to answer

118. After your **most recent** baby was born or your **most recent** pregnancy ended, did a doctor, nurse, or other health care worker tell you that you had depression?

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

I don't know

I prefer not to answer

119. Please tell us anything else about your experience with pregnancy or family planning.

120. Did anyone help you fill out this survey?

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

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

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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.