Form Approved
OMB No. 0920-New
Expiration Date: XX/XX/XXXX



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 STAR*net*). Additional information on MD STAR*net* can be found at the following

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!

Public reporting burden of this collection of information is estimated to average 20 minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to CDC/ATSDR Reports Clearance Officer; 1600 Clifton Road NE, MS D-74, Atlanta, Georgia 30333; Attn: OMB-PRA (0920-New)

Form Approved / OMB No. 0920-New / Exp. date xx/xx/XXXX

Participant ID:	

INSTRUCTIONS	5. Do you own or rent your home?
Mark your answer by completely filling in the	□ Own
circle or marking an X in the box to the left of	☐ Rent
your answer.	☐ Other arrangement
A doctor or health care provider	☐ I don't know
A family member	\square I prefer not to answer
Use a black or blue pen, if available.	·
Ose a black of blue peri, if available.	6. What is your current employment status?
The first set of guestions are about you and	\square Employed for wages \rightarrow Go to Next
The first set of questions are about you and your household.	Question
your nousenoid.	☐ Self-employed→ Go to Next Question
1 What is your athnicity?	☐ Out of work for a year or more
1. What is your ethnicity?	☐ Out of work for less than a year
START HERE	☐ Homemaker
☐ Hispanic or Latino	☐ Student
☐ Not Hispanic or Latino	☐ Retired
Li Not Hispanic of Latino	☐ Unable to work
2. What race do you identify with?	☐ Other, please specify:
Please check all that apply.	☐ I don't know
☐ American Indian/Alaskan Native	☐ I prefer not to answer
☐ Asian	·
☐ Black or African American	7. If employed, how many hours per week are
☐ Native Hawaiian or Pacific Islander	you working?
☐ White	☐ Less than 20 hours per week
☐ Other	☐ 20-40 hours per week
2 00.101	☐ More than 40 hours per week
3. Are you currently attending a school or	☐ I don't know
college?	☐ I prefer not to answer
□ Yes	
□ No	8. During the last 12 months, what was your
☐ I don't know	yearly total household income before taxes?
☐ I prefer not to answer	□ \$40 to \$9,999
F	□ \$10,000 to \$24,999
4. What is the highest level of education yo	ou □ \$25,000 to 49,999
completed?	□ \$50,000 to 74,999
☐ Elementary school (grades 1 through 8)	□ \$75,000 to 99,999
☐ Some high school (grades 9 through 11)	□ \$100,000 to 149,999
☐ Graduated high school (grade 12)	\square \$150,000 and greater
☐ Some college or technical school	☐ I don't know
☐ Graduated college or technical school	☐ I prefer not to answer
☐ Graduate school	
☐ I don't know	
☐ I prefer not to answer	

	following questions are about COVID-19			I do not like vaccines or needles
and	influenza.			I am not worried about getting COVID-19
9.	To your knowledge, have you had COVID-1 ☐ Yes	.9?		I already had COVID-19 I have a medical condition that prevents me from getting the vaccine
	□ No → Go to question 13			I do not think the vaccine is effective
	☐ I don't know → <i>Go to 13</i>			I just don't want the vaccine
	☐ I prefer not to answer → Go to 13			Other, specify:
				I don't know
	Was your infection confirmed by a test? Yes, confirmed by test			I prefer not to answer
	No, not confirmed by test	:	15.	Have you ever received a flu vaccine?
	I don't know			☐ Yes
	I prefer not to answer			□ No → Go to question 17
				☐ I don't know → Go to question 18
				\square I prefer not to answer \rightarrow Go to 18
11.	Describe the level of care you received.			
	Did not seek medical care	:	16.	Did you receive the flu vaccine any time in the
	Received medical care but was not			last 12 months?
	hospitalized			\square Yes \rightarrow Go to question 18
	Was hospitalized			□ No
	I don't know			☐ I don't know → Go to 18
	I prefer not to answer			\square I prefer not to answer \rightarrow Go to 18
	How would you characterize your symptoms	s? :	17.	What are the reasons you have not received
	No symptoms			the flu vaccine during the past 12 months?
	Mild (e.g., low-grade fever, cough, shortnes	S		(Check all that apply)
	of breath)			I would like to get it but have not been able to
	Moderate (e.g., moderate difficulty breathing	g,		I am worried about the side effects of the
	body aches, fatigue)			vaccine
	Severe (e.g., severe difficulty breathing,			I do not like vaccines or needles
	persistent pain, inability to stay awake)			I am not worried about getting the flu
	I don't know			I already had the flu
	I prefer not to answer			I have a medical condition that prevents me
			_	from getting the vaccine
13.	Have you received a COVID-19 vaccine?			I do not think the vaccine is effective
	☐ Yes → Go to question 15			I just don't want the vaccine
	□ No			Other, specify:
	\square I don't know \rightarrow Go to 15			I don't know
	\square I prefer not to answer \rightarrow Go to 15		П	I prefer not to answer
		_	The	next set of questions ask about your
				erience with chronic pain and fatigue
				ted to your muscular dystrophy.
		ĺ	Cia	teu to your muscular dystrophly.
			18	3. In the past 30 days , how many days have
				you experienced pain related to your
				muscular dystrophy in any part of your body?
14.	What are the reasons you have not receive	d a		□ number of days
	COVID-19 vaccine? (Check all that apply)			☐ I cannot recall having muscular dystrophy-
	I would like to get it but have not been able	to		related pain in the last 30 days \rightarrow Go to
	I am worried about the side effects of the			question 52
	vaccine			\square I prefer not to answer \rightarrow Go to 52

19. Is your pain managed by medication or other methods?	☐ Not in the last month☐ I don't know
☐ Yes	☐ I prefer not to answer
 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 	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	☐ 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	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	 □ 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
☐ Not in the last month ☐ 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
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	 □ No → Go to question 34 □ I don't know → Go to 34 □ I prefer not to answer → Go to 34
 □ Provide some relief but not enough that I can resume normal activities □ Provide little or no pain relief □ I don't know 	32. How frequently do you use any combination of this type of medication to manage your pain? ☐ Every day ☐ 2-6 days per week
☐ 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	 ☐ Once a week ☐ Once a month ☐ Not in the last month ☐ I don't know ☐ I prefer not to answer
dystrophy? ☐ Yes ☐ No → Go to question 31 ☐ I don't know→ Go to 31 ☐ I prefer not to answer → Go to 31	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
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	☐ 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
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	

34. Do you use nonpharmacological methods	☐ Not in the last month
such as biofeedback, physical therapy,	☐ I don't know
behavioral modifications, better sleep	\square I prefer not to answer
practices, better hygiene practices, or diet t	
manage the pain related to your muscular	40. How helpful are any combination of these
dystrophy?	other methods in managing your pain?
□ Yes	☐ Completely relieve the pain
□ No → Go to question 37	☐ Reduce pain so I can manage my normal
☐ I don't know→ Go to 37	activities
\square I prefer not to answer \rightarrow Go to 37	\square Provide some relief but not enough that I
	can resume normal activities
35. How frequently do you use any combination	n Provide little or no pain relief
of these methods to manage your pain?	☐ I don't know
☐ Every day	\square I prefer not to answer
☐ 2-6 days per week	
☐ Once a week	The next questions ask about the intensity of
☐ Once a month	your pain. For each item, please mark the
☐ Not in the last month	option that best describes the intensity of your
☐ I don't know	pain during the indicated time-period.
☐ I prefer not to answer	y 3
,	41. In the past 7 days , how intense was your
36. How helpful are any combinations of these	pain at its worst?
methods in managing your pain?	□ No pain
☐ Completely relieve the pain	☐ Mild
☐ Reduce pain so I can manage my normal	
activities	□ Severe
☐ Provide some relief but not enough that I	☐ Very severe
can resume normal activities	☐ I don't know
☐ Provide little or no pain relief	☐ I prefer not to answer
☐ I don't know	in prefer flot to answer
☐ I prefer not to answer	42. In the past 7 days, how intense was your
Li prefer flot to answer	average pain?
37. Do you use any other method or therapy to	<u> </u>
manage your pain?	☐ Mild
☐ Yes	☐ Moderate
□ No → Go to question 41	☐ Severe
☐ I don't know→ Go to 41	☐ Very severe
I prefer not to answer \rightarrow Go to 41	☐ I don't know
i prefer flot to answer → GO to 41	☐ I prefer not to answer
38. What other methods or therapies do you	☐ I prefer not to answer
•	
use?	20
	39.
	39.
	39.
	39.
	39.
Llow from onthy do you was any and in a	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	

Participant ID: _____

Page 6/17 **F**

43. What is your level of pain right now?	\square I prefer not to answer
□ No pain	
☐ Mild	48. In the past 7 days, how much did pain
☐ Moderate	interfere with the things you usually do for
☐ Severe	fun?
☐ Very severe	\square Not at all
☐ I don't know	☐ A little bit
☐ I prefer not to answer	☐ Somewhat
,,	☐ Quite a bit
The next questions are about the impact	· · · · · · · · · · · · · · · · · · ·
pain on your activities. For each item, plea	
mark the option that best describes how of	
the impact of pain occurred in the past 7 days	
the impact of pain occurred in the past r day.	49. In the past 7 days , how much did pain
44. In the past 7 days, how much did pain	interfere with your enjoyment of social
interfere with your day to day activities?	activities?
□ Not at all	□ Not at all
☐ A little bit	☐ A little bit
☐ Somewhat	☐ Somewhat
☐ Quite a bit	☐ Quite a bit
☐ Very much	☐ Very much
☐ I don't know	☐ I don't know
☐ I prefer not to answer	☐ I prefer not to answer
45. In the past 7 days, how much did pain	50. In the past 7 days, how much did pain
interfere with work around the home?	interfere with your enjoyment of life?
□ Not at all	□ Not at all
☐ A little bit	☐ A little bit
□ Somewhat	☐ Somewhat
☐ Quite a bit	☐ Quite a bit
□ Very much	☐ Very much
☐ I don't know	☐ I don't know
☐ I prefer not to answer	☐ I prefer not to answer
46. In the past 7 days, how much did pain	51. In the past 7 days, how much did pain
interfere with your ability to participate in	interfere with your family life?
social activities?	☐ Not at all
☐ Not at all	☐ A little bit
☐ A little bit	☐ Somewhat
☐ Somewhat	☐ Quite a bit
☐ Quite a bit	☐ Very much
☐ Very much	☐ I don't know
☐ I don't know	☐ I prefer not to answer
☐ I prefer not to answer	in prefer not to answer
in protest flot to allower	
47. In the past 7 days, how much did pain	
interfere with your household chores?	
□ Not at all	The next questions are about how tired you
☐ A little bit	felt during the past week and how feeling tired
□ Somewhat	impacted your daily activities. In the past 7
☐ Quite a bit	days, how often was each of the following
☐ Very much	statements true? Please respond to each
☐ I don't know	statement by marking the best answer.

52. I felt exhausted.	things I wanted to do.	
☐ Never	☐ Never	
Rarely	☐ Rarely	
☐ Sometimes	□ Sometimes	
☐ Often	□ Often	
☐ Always	☐ Always	
☐ I don't know	☐ I don't know	
☐ I prefer not to answer	☐ 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	58. I felt tired. □ 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	59. I had to limit my social activity bec tired. Never Rarely Sometimes Often Always I don't know I prefer not to answer If your response to all of the stateme was 'Never' or 'Rarely', please go to	ents 52-59
☐ Sometimes ☐ Often ☐ Always ☐ I don't know ☐ I prefer not to answer	61.	question
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

ou. How have you managed your latigue in the	\Box i prefer not to answer \rightarrow GO tO 66
past 7 days? Please check all that apply.	05 11 11 11 11 11
☐ Stimulants	65. How did speaking with this person affect your
□ Exercise	decision to have (more) children?
☐ Coffee and/or other caffeine containing	☐ It did not/will not affect my decision to have
beverages	children
☐ Prescription medications	☐ I decided not to have my own children
☐ Non-prescription medications	☐ I decided to adopt
☐ Dietary Supplements	☐ I decided to see a medical provider who
☐ Sleep	could help me have children without muscular
☐ Herbal remedies	dystrophy
☐ Other, specify	☐ Other, specify:
☐ I don't know	
☐ I prefer not to answer	
·	☐ I don't know
61. Please tell us anything else about your	☐ I prefer not to answer
experience with pain or fatigue.	'
, p. 1 . 1 . 1 . 1 . 2 . 2 . 3 . 1	66. Have you ever been pregnant?
	☐ Yes
	□ No
	☐ I don't know
	\square I prefer not to answer
	·
	67. Did you ever have trouble getting pregnant or
	were unable to get pregnant?
	☐ Yes
	□ No
The next questions are about your experience	☐ I have not tried to get pregnant
family planning.	☐ I don't know
January Planning.	\square I prefer not to answer
62. At what age were you diagnosed with	·
muscular dystrophy?	68. Were you ever told by a medical provider that
	you would not be able to get pregnant or might
□ I don't know	have a hard time getting pregnant due to your
☐ I prefer not to answer	muscular dystrophy?
_ i protor not to anomor	☐ Yes
63. Have you ever talked with a genetic	□ No
counselor or other medical provider about the	□ I don't know
chance for your children or other family	\square I prefer not to answer
members to have muscular dystrophy?	·
☐ Yes	69. Did you ever decide not to become
☐ No → Go to question 66	pregnant because it would be a risk to your
☐ I don't know→ Go to 66	own health?
☐ I prefer not to answer→ <i>Go to 66</i>	□ Yes
E i protot flot to allower i Go to Go	□ No
64. When did you talk with the genetic counselor	
or medical provider?	i don't knew
☐ Before considering or having children	☐ I prefer not to answer
☐ During one of my partner's pregnancies	Next, we are going to ask some questions
☐ Between my partner's pregnancies	about your pregnancies.
☐ After I was done having children → Go to	about your pregnancies.
question 66	70. How many times have you been pregnant,
☐ I don't remember/I don't know → Go to 66	including pregnancies that may have ended
	J. 3

Page 9/17 **F**

Participant ID: _____

or molar pregnancy?	pregnancy? If you carried more than one
□ times	baby, please check all that apply.
☐ I don't know	☐ Baby was born alive at less than 37
☐ I prefer not to answer	weeks of pregnancy (early or preterm)
·	☐ Baby was born alive at 37 weeks or
71. In your <i>first</i> pregnancy, how many	later (term)
babies were you carrying?	☐ Miscarriage (fetal loss) before 20
	weeks of pregnancy
2 (twins)	☐ Stillbirth (fetal loss) at 20 weeks of
☐ 3 or more (triplets or more)	pregnancy or later
☐ I don't know	☐ Abortion (pregnancy medically ended for any reason)
☐ I prefer not to answer	□ I don't know
If you have never been pregnant, skip to	☐ I prefer not to answer
Q119.	76. When did this pregnancy end?
72. What was the outcome(s) of the	/ (mm/yyyy)
pregnancy? <i>If you carried more than one</i>	☐ I don't know
baby, please check all that apply.	\square I prefer not to answer
☐ Baby was born alive at less than 37	If you only had two pregnancies, please go to
weeks of pregnancy (early or preterm)	question 86.
Baby was born alive at 37 weeks or	77. In your <i>third</i> pregnancy, how many
later (term)	babies were you carrying?
☐ Miscarriage (fetal loss) before 20	
weeks of pregnancy	□ 2 (twins)
☐ Stillbirth (fetal loss) at 20 weeks of pregnancy or later	□ 3 or more (triplets or more)
☐ Abortion (pregnancy medically	☐ I don't know
ended for any reason)	
☐ I don't know	☐ I prefer not to answer
☐ I prefer not to answer	78. What was the outcome(s) of the
·	pregnancy? If you carried more than one
73. When did this pregnancy end?	baby, please check all that apply.
/ (mm/yyyy)	Baby was born alive at less than 37
☐ I don't know	weeks of pregnancy (early or preterm)
☐ I prefer not to answer	☐ Baby was born alive at 37 weeks or later (term)
f you only had one pregnancy, <i>please go to</i>	☐ Miscarriage (fetal loss) before 20
question 86.	weeks of pregnancy
74. In your second pregnancy, how	☐ Stillbirth (fetal loss) at 20 weeks of
many babies were you carrying?	pregnancy or later
	☐ Abortion (pregnancy medically
□ 2 (twins)	ended for any reason)
□ 3 or more (triplets or more)	☐ I don't know
☐ I don't know	☐ I prefer not to answer
☐ I prefer not to answer	·
	79. When did this pregnancy end?
	/ (mm/vvvv)

75.

What was the outcome(s) of the

Page 10/17 **F**

in miscarriages, stillbirths, abortion, or a tubal

Participant ID: _____

		I don't know	84. What was the outcome(s) of the
_		I prefer not to answer	pregnancy? If you carried more than one
			baby, please check all that apply.
	If was and		☐ Baby was born alive at less than 37
	-	y had three pregnancies, please go to	weeks of pregnancy (early or preterm)
	question	80.	☐ Baby was born alive at 37 weeks or
	80.	In your <i>fourth</i> pregnancy, how	later (term)
	many	babies were you carrying?	☐ Miscarriage (fetal loss) before 20
		1	weeks of pregnancy
		2 (twins)	☐ Stillbirth (fetal loss) at 20 weeks of
		3 or more (triplets or more)	pregnancy or later
		I don't know	☐ Abortion (pregnancy medically
		I prefer not to answer	ended for any reason)
			☐ I don't know
	81.		☐ I prefer not to answer
		ancy? If you carried more than one	85. When did this pregnancy end?
		please check all that apply.	/ (mm/yyyy)
	□ wook	Baby was born alive at less than 37 s of pregnancy (early or preterm)	/ (\\\\\\\\\\\\\\\\\\\\\\\\\\\
	_		☐ I prefer not to answer
	□ later (Baby was born alive at 37 weeks or	-
		Miscarriage (fetal loss) before 20	The following questions are about the <i>first</i> time you were pregnant.
		s of pregnancy	you were pregnant.
		Stillbirth (fetal loss) at 20 weeks of	86. How old were you when you
		ancy or later	became pregnant with your <i>first</i> pregnancy?
		Abortion (pregnancy medically	years
		d for any reason)	☐ I don't know
		I don't know	☐ I prefer not to answer
		I prefer not to answer	87. Did you or your partner use any of
		·	the following assisted technologies to get
	82.	When did this pregnancy end?	pregnant with your <i>first</i> pregnancy? <i>Please</i>
		(mm/yyyy)	check all that apply
		I don't know	☐ No assistance needed
		I prefer not to answer	☐ Hormone therapy or medications
			☐ In-vitro fertilization (IVF)
	If you onl	ly had four pregnancies, please go to	☐ Pre-implantation diagnosis. (Genetic
	question		testing of the embryo before implantation
	-		following IVF)
	83.	In your <i>fifth</i> pregnancy, how many	☐ Artificial insemination with your
		s were you carrying?	partner's sperm
		1	☐ Artificial insemination with donor
		2 (twins)	sperm
		3 or more (triplets or more)	☐ Drugs to improve ovulation
		I don't know	☐ Surgery to correct blocked tubes
		I prefer not to answer	☐ Treatment for varicocele
			☐ Other types of medical help
			☐ I don't know

		I prefer not to answer			-		how your
8	88.	Did you have any of the following	3	muscular	dystrophy r first pregn	•	s changed
		s with your first pregnancy? Ple	ase			_	
		II that apply.					of muscular ne symptom
-		No problems			•	st pregnancy	
-	□ blood pr	Gestational Hypertension (high		_			
	pregnan	essure that started during this		91. muscl	During you e weakness	ır pregnancy,	was your
_		Pre-eclampsia or eclampsia			Worse		
I		Significant bleeding with delivery			Better		
[Significant bleeding while pregna			About the	same	
I		Infection				ve muscle we	akness
[Gestational diabetes (diabetes the	nat		e or during pr		
5	started (during this pregnancy)			I don't kno	W	
I		Too much amniotic fluid			I prefer no	t to answer	
I		Too little amniotic fluid		92 During	vour pregnai	ncy, was your	muscle
-		Labor pains more than 3 weeks		pain	your program	noy, was your	massic
	before n labor)	ny baby was due (preterm or earl	У		Worse		
	П	Water broke more than 3 weeks			Better		
i	– before y	our baby was due (preterm			About the	same	
		re rupture of membranes or			Did not ha	ve pain befor	e or during
	PPROM —	'		pregn	=		
	□ during d	Bad reaction to the anesthetic us	sed		I don't kno		
	_	I don't know			I prefer no	t to answer	
		I prefer not to answer		93.		ır pregnancy,	were your
		•			e cramps		
_		pregnancy did not end in a liv se go to question 91.	е		Worse		
	•				Better		
	89. —	How was your first baby delivered	ed?		About the		
-		Unassisted vaginal delivery		or dur	not na חסל na ing pregnanc	ve muscle cra	amps before
	Uacuum	Assisted vaginal delivery (forcep extraction)	s or		I don't kno	=	
		Planned cesarean section				t to answer	
-		Unplanned cesarean section,			•		
-		g emergency C-section		94. difficu	טטיוות buring you Ity you had w	ır pregnancy, zalking	was any
I		I don't know			Worse	aiking	
I		I prefer not to answer			Better		
(90.	Did your first baby have any of t	he		About the	same	
		g problems?	i i C			ve difficulty w	alking
		Born too small (Low birth weight)		before	e or during pr		9
I		Died before she/he was 1 month			I don't kno	W	
		Neither of these problems			I prefer no	t to answer	
I		I don't know		95.	During vol	ır pregnancy,	did you
I		I prefer not to answer				th daily activit	
	Particip	ant ID:			Pa	age 12/17 F	

□ Yes	\square About the same
□ No	Did not have difficulty walking
☐ About the same	before, during or after pregnancy
☐ Did not need help with daily	☐ I don't know
activities before or during my pregnancy	☐ I prefer not to answer
☐ I don't know	
☐ I prefer not to answer	
Now, please tell me how each of the following symptoms of muscular dystroph changed after your first pregnancy ended compared to your symptoms during the pregnancy.	y 100. After your pregnancy ended, did you need more help with daily activities than you did during your pregnancy? □ Yes □ No
96. After your pregnancy ended, was	
your muscle weakness	
□ Worse	☐ Did not need help with daily activities before, during or after my
□ Better	pregnancy
☐ About the same	☐ I don't know
☐ Did not have muscle weakness before, during or after pregnancy	☐ I prefer not to answer
☐ I don't know	101. Did any symptoms related to
☐ I prefer not to answer	muscular dystrophy in your first pregnancy
97. After your pregnancy ended, was	affect your decision to have future pregnancies?
your muscle pain	□ Yes
□ Worse	□ No
□ Better	☐ I don't know
☐ About the same	☐ I prefer not to answer
 Did not have pain before, during cafter pregnancy 	102. After your first pregnancy, did a doctor, nurse, or other health care worker
☐ I don't know	tell you that you had depression?
☐ I prefer not to answer	□ Yes
98. After your pregnancy ended, were	∆ □ No
your muscle cramps	☐ I don't know
□ Worse	☐ I prefer not to answer
□ Better	If you only had one pregnancy, please go to
☐ About the same	question 119
☐ Did not have muscle cramps befo	•
during or after pregnancy	The following questions are about the most recent or last time you were pregnant.
☐ I don't know	
☐ I prefer not to answer	103. How old were you when you
00 After your programmy anded was	became pregnant with your most recent pregnancy?
99. After your pregnancy ended, was any difficulty you had walking	years
□ Worse	☐ I don't know
☐ Better	☐ I prefer not to answer
	·
Participant ID:	Page 13/17 F

the following assistive technologies to get pregnant with your most recent pregnancy?	birth, please go to question 119.]
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)	106. Did your most recent baby 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
□ Artificial insemination with 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	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 105. Did you have any of the following problems with your most recent pregnancy? Please check all that apply. ☐ No problems	☐ I prefer not to answer The next questions are about if and how your muscular dystrophy symptoms changed during your last pregnancy.
☐ Gestational Hypertension (high blood pressure that started during this pregnancy) ☐ Pre-eclampsia or eclampsia	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.
□ 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	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
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 PPROM) Bad reaction to the anesthetic used during delivery	☐ 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
☐ I don't know☐ I prefer not to answer	pregnancy I don't know
Participant ID:	Page 14/17 F

☐ I prefer not to answer	113. After your most recent pregnancy
110. During your pregnancy, were your	ended, was your muscle weakness ☐ Worse
muscle cramps	
□ Worse	□ Better
□ Better	☐ About the same
☐ About the same	☐ Did not have muscle weakness before, during or after pregnancy
☐ Did not have muscle cramps before	☐ I don't know
or during pregnancy	☐ I prefer not to answer
☐ I don't know	·
☐ I prefer not to answer	114. After your most recent pregnancy
111. During your pregnancy, was any	ended, was your muscle pain
difficulty you had walking	□ Worse
□ Worse	□ Better
□ Better	☐ About the same
☐ About the same	☐ Did not have pain before, during or after pregnancy
☐ Did not have difficulty walking	☐ I don't know
before or during pregnancy	☐ I prefer not to answer
☐ I don't know	·
☐ I prefer not to answer	115. After your most recent pregnancy
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	
	ended, were your muscle cramps □ Worse □ Better
	☐ About the same
Now, please tell me how each of the following	Did not have muscle cramps before,
symptoms changed after your <i>most recent</i>	during or after pregnancy
<i>pregnancy</i> ended compared to your symptoms during your <i>most recent pregnancy</i> .	☐ I don't know
	I prefer not to answer
Participant ID:	Page 15/17 F

116.	After your most recent pregnancy			I don't know	
	was any difficulty you had walking Worse			I prefer not to answer	
	Better				
	About the same		119.	Please tell us anything else	e about
			•	sperience with pregnancy or	family
	Did not have difficulty walking during or after pregnancy		plannin	ıg.	
	I don't know				
	I prefer not to answer		120.	Did anyone help you fill ou	t this
117			survey		t tillo
117.	After your most recent pregnancy, need more help with daily activities			Yes	
	u did during your pregnancy?			No → end	
	Yes			I prefer not to answer \rightarrow er	nd
	No		121.	What is the relationship of	the
	About the same			who helped you fill out this	
	Did not need help with daily				
	s before, during or after my				
pregnai	-				
	I don't know			d of the survey. Thank you f	
	I prefer not to answer			swer our questions. Your ar better understand the lives	
118.	After your most recent baby was	with n		dystrophy and can inform of	
	your most recent pregnancy ended octor, nurse, or other health care	, make	rs who p	plan services to support peo	
	tell you that you had depression?	musc	ular dyst	trophy and their families.	
	Yes				
	No				
	I prefer not to answer → end				
	•				