Supplement



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In this study we would like to gather information from Duchenne muscular dystrophy (DMD) patients who have lower extremity edema (swelling) to learn how to better treat it. There are no direct benefits to you for participating in this study, including financial compensation. There is no cost to participate in this study. However, this research may help others with DMD. Please read this page carefully, proceeding only if you meet the following criteria.

Responding to this survey is entirely voluntary and should only take 15 minutes to complete. There is always a risk of participation in research. To prevent your medical information from being reviewed by people unrelated to this study, your responses will be shared without identifying information and in aggregate. You may choose to answer only some of the questions or not to complete the survey at all. It will not affect your quality of care. Completing the survey will imply your consent to participate. No medical advice will be offered based on the information collected from the survey. If you have a concern, please contact your physician. The information collected from this survey maybe kept by the investigators for potential future unspecified research.

Inclusion criteria for completing the survey:

1. You must have DMD.
2. You must be male.
3. You must be at least 15 years old.
4. You must have lower extremity edema (swelling).

Exclusion criteria for completing the survey:

1. You are unwilling to answer the questions on the survey.
2. Do not read, write or speak English.

Would you like to complete the survey?

1. Yes\*
2. No\*\*

Section I: Demographics

1. Do you have DMD?
   1. Yes
   2. No+
2. How old are you? Please write your age on the line below.

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1. Are you a male?
   1. Yes
   2. No+
2. Do you have swelling in your feet?
   1. Yes
   2. No
3. Do you have swelling between the knees and feet?
   1. Yes
   2. No

**If you answered “No” to both questions 4 and 5, then please stop the survey. Unfortunately, you are not eligible for our study.**+

Section II: Medical History

1. Have you been told that your heart function is below normal?
   1. Yes
   2. No
   3. Not sure
2. Are you on any of the following medications? Please select all that apply.
   1. ACE inhibitor (captopril, enalapril, lisinopril, ramipril)
   2. Beta blocker (atenolol, carvedilol, metoprolol, propranolol, bisoprolol)
   3. Entresto (sacubitril/valsartan)
   4. Diuretics [furosemide (Lasix), chlorothiazide (Diuril)]
   5. Spironolactone or eplerenone
   6. Digoxin
   7. None
3. Do you use respiratory support? Please select all that apply.
   1. CPAP
   2. BiPAP
   3. Sip ventilator
   4. Ventilator by tracheostomy
   5. None
4. Can you walk independently for any period of time?
   1. Yes
   2. No
5. Do you use a wheelchair/powerchair?
   1. Yes
   2. No (**please** **skip to question 8**)
6. While awake, how much time do you spend in a wheelchair/powerchair each day?
   1. None
   2. Less than 3 hours
   3. 3-6 hours
   4. 6-12 hours
   5. 12-18 hours
   6. Greater than 18 hours
7. Do you sleep in your wheelchair/powerchair?
   1. Yes
   2. No
8. Do you sleep with your feet elevated (feet level with the knees or higher)?
   1. Yes
   2. No
9. How many times per day do you elevate your feet (feet level with the knees or higher)?
   1. None
   2. 1-3
   3. 3-5
   4. Greater than 5
10. How long do you elevate your feet?
    1. 0-5 minutes
    2. 6-10 minutes
    3. 11-15 minutes
    4. 16-20 minutes
    5. More than 20 minutes

Section III: Edema

1. When did your swelling start?
   1. Greater than 1 year ago
   2. 6 months to 1 year ago
   3. Less than 6 months ago
   4. Not sure
2. Rate your current swelling based on the following picture below.
   1. Normal
   2. Mild
   3. Moderate to severe

Lymphatic Drainage Massages for Edema, <http://www.santephysique.com/blog/does-lymphedema-need-to-be-treated/>

Accessed: 4/29/2019

1. Use one finger and push for 5 seconds on the most swollen part of your leg/foot. Was an impression left in the skin when you lifted your finger? (If you are unable to do this yourself, please ask someone to help you.)
   1. Yes
   2. No
2. Rate your severity based on the following picture below.
   1. None
   2. Mild
   3. Moderate
   4. Severe

Slide 29 of “Abdominal Examination and the Assessment of Fluid Accumulation”

<https://slideplayer.com/slide/5757852/>

Accessed: 4/29/2019

1. Have you had any sores, skin breakdown or infections of your feet or below your knees?
   1. Yes
   2. No
2. Have you ever been prescribed any of the following for your swelling? Please select all that apply.
   1. Physical therapy
   2. Therapeutic massage
   3. Compression socks
   4. ACE bandage wraps
   5. Pneumatic pump
   6. None (**please skip to question 8**)
3. Did the therapy/therapies help?
   1. Yes
   2. No
   3. Not sure
4. Does elevating your feet improve your swelling?
   1. Yes
   2. No
   3. Not sure
5. Have you ever been prescribed a diuretic (water pill) for your swelling?
   1. Yes
   2. No (**please skip to question 11**)
6. Did it help?
   1. Yes
   2. No
7. Has anything helped your swelling and what therapies have you tried that have not been mentioned in this survey? Please write your response on the lines below.

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Thank you for your responses. Your answers will help us learn more about treating lower extremity edema in DMD patients.

If you have any questions or concerns, please feel free to contact the researchers responsible for this study. Their contact information is as follows:

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