

ELECTRONIC SUPPLEMENTARY MATERIAL

Prevalence and Risk of Falls and Fractures in the Idiopathic Inflammatory Myopathies: A Cross-Sectional Study of 470 Patients

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Myositis Support and Understanding Questionnaire

Patients Myositis Journey & Burden of Disease Survey



This survey seeks to understand your myositis journey and the burden of the disease - financially, physically, and mentally.

Your valuable input will greatly help the overall understanding and learning on myositis care. Please complete the survey below, it will take roughly 8 minutes of your time. Your honest responses will be highly appreciated!

Thank you!

Demographic Information

This section will collect basic information of patients that will be de-identified and used for research purposes.

How old are you?

- ☐ 18 or less
- ☐ 19-29
- ☐ 30-39
- ☐ 40-49
- ☐ 50-59
- ☐ 60-69
- ☐ 70-79
- ☐ 80-89
- ☐ 90-99
- ☐ 100+

What is your biological sex?

- ☐ Female
- ☐ Intersex
- ☐ Male
- ☐ Prefer not to answer

How do you describe yourself?

- ☐ Asian or Pacific Islander
- ☐ Black or African American
- ☐ Native/indigenous
- ☐ White or Caucasian
- ☐ Biracial
- ☐ Multiracial
- ☐ Other
- ☐ Prefer not to answer

What is your ethnicity?

- ☐ Hispanic/Latino
- ☐ Not Hispanic/Latino
- ☐ Prefer not to answer

What is your current employment status?

- ☐ Working Full Time (>40 hours/week)
- ☐ Working Part Time (up to 39 hours per week)
- ☐ On leave but still employed
- ☐ Unemployed and currently looking for work
- ☐ Unemployed and not currently looking for work
- ☐ Unemployed due to health-related reasons and looking for work

- ☐ Unemployed due to health-related reasons and not looking for work
- ☐ Student
- ☐ Homemaker
- ☐ Retired
- ☐ Self-employed
- ☐ Receiving disability payments
- ☐ Other
- ☐ Prefer not to answer

What is your marital status?

- ☐ Single
- ☐ Married or in a domestic partnership
- ☐ Widowed, divorced, or separated
- ☐ Prefer not to answer

What is your highest level of education?

- ☐ Less than a high school diploma
- ☐ High school degree or equivalent
- ☐ Some college, no degree
- ☐ Associate degree
- ☐ Bachelor's degree
- ☐ Master's degree
- ☐ Professional degree
- ☐ Doctorate

Your Myositis Journey

This section will collect information about your myositis diagnosis and associated treatments to better understand the timeline of disease.

What type of myositis do you have?

- ☐ Dermatomyositis
- ☐ Polymyositis
- ☐ Anti-synthetase syndrome
- ☐ Immune mediated necrotizing myopathy
- ☐ Inclusion body myositis
- ☐ Mixed connective tissue disorder/ overlap myositis
- ☐ Other
- ☐ Not yet diagnosed

How were you diagnosed with myositis (check all that apply)?

- ☐ Antibody
- ☐ Muscle biopsy
- ☐ Skin biopsy
- ☐ MRI of muscle
- ☐ Response to treatment
- ☐ Other
- ☐ None of the above

When did your symptoms start? Please enter your best estimate of the month, day, and year in the following format: MM-DD-YYYY.

M-D-Y

When were you diagnosed? Please enter your best estimate of the month, day, and year in the following format: MM-DD-YYYY.

M-D-Y

Who primarily manages your myositis?

- ☐ Neurologist
- ☐ Neuromuscular specialist
- ☐ Immunologist
- ☐ Rheumatologist
- ☐ Primary care provider
- ☐ Other
- ☐ None

**Which specialists do you follow up with for your myositis?
(Select all that apply)**

- ☐ Neurologist
- ☐ Neuromuscular specialist
- ☐ Rheumatologist
- ☐ Dermatologist
- ☐ Pulmonologist
- ☐ Orthopedic Surgeon
- ☐ Other
- ☐ None

Approximately how many healthcare providers did you see before obtaining a diagnosis of myositis?

- ☐ 1-2
- ☐ 3-4
- ☐ 5-7
- ☐ 8-10
- ☐ 11 or higher

When you were finally diagnosed with myositis, how far did you have to travel to see the doctor/specialist/center of excellence who diagnosed you?

- ☐ 1-20 miles
- ☐ 21-50 miles
- ☐ 51-100 miles
- ☐ 101-500 miles
- ☐ 501+ miles

Financial Burden

We want to understand how your financial wellness correlates with your myositis journey and outcomes.

What form of insurance did you have when you were seeking a diagnosis?

- ☐ Private high deductible (deductible greater than \$1400 for individuals or \$2800 for families)
- ☐ Private low deductible (deductible less than \$1400 for individuals or \$2800 for families)
- ☐ Medicare
- ☐ Medicaid
- ☐ Tricare/Military
- ☐ Non-USA based national/universal healthcare (eg, National Health Service or Canadian Medicare)
- ☐ Uninsured
- ☐ Other
- ☐ Don't know

What form of insurance do you currently have?

- ☐ Private high deductible (deductible greater than \$1400 for individuals or \$2800 for families)
- ☐ Private low deductible (deductible less than \$1400 for individuals or \$2800 for families)
- ☐ Medicare
- ☐ Medicaid
- ☐ Tricare/Military
- ☐ Non-USA based national/universal healthcare (eg, National Health Service or Canadian Medicare)
- ☐ Uninsured
- ☐ Other
- ☐ Don't know

What is your household yearly income?

- ☐ Less than \$20,000
- ☐ \$20,000 to \$34,999
- ☐ \$35,000 to \$49,999
- ☐ \$50,000 to \$74,999
- ☐ \$75,000 to \$99,999
- ☐ \$100,000 to \$149,999
- ☐ Over \$150,000
- ☐ Prefer not to answer

How much do you worry about financial problems that have resulted from your myositis diagnosis and treatment?

- ☐ Not at all
- ☐ A little bit
- ☐ Somewhat
- ☐ Quite a bit
- ☐ Very much

How has myositis affected your finances? Please check all that apply

- ☐ I had to use savings
- ☐ I had to borrow money or take out a loan
- ☐ I could not make payments on credit cards or other bills
- ☐ I cut down on spending for food and/or clothes
- ☐ I cut down on spending for health care for other family members
- ☐ I cut down on recreational activities
- ☐ I cut down on expenses in general
- ☐ Remaining status quo, no pressure yet

Quality of Life Questionnaire

This section is to assess the social and psychological difficulties patients with myositis face daily. This information will be used to examine the social burden of disease so in the future, healthcare providers can provide more robust/holistic care to myositis patients.

	Not at all	A little bit	Somewhat	Quite a bit	Very much
Lately because of my illness, some people avoided me	☐	☐	☐	☐	☐
Lately because of my illness, I felt left out of things	☐	☐	☐	☐	☐

Lately because of my illness, people avoided looking at me	☐	☐	☐	☐	☐
Lately because of my illness, I felt embarrassed about my illness	☐	☐	☐	☐	☐
Lately because of my illness, some people seemed uncomfortable with me	☐	☐	☐	☐	☐
Lately because of my illness, some people acted as though it was my fault I have this illness	☐	☐	☐	☐	☐
	Never	Rarely	Sometimes	Often	Always
I have a sense of well-being	☐	☐	☐	☐	☐
I feel hopeful	☐	☐	☐	☐	☐
My life is satisfying	☐	☐	☐	☐	☐
My life has purpose	☐	☐	☐	☐	☐
My life has meaning	☐	☐	☐	☐	☐
I feel cheerful	☐	☐	☐	☐	☐
I have a sense of balance in my life	☐	☐	☐	☐	☐
Many areas of my life are interesting to me	☐	☐	☐	☐	☐
	I am not at all confident	I am a little confident	I am somewhat confident	I am quite confident	I am very confident
I can handle negative feelings	☐	☐	☐	☐	☐
I can find ways to manage stress	☐	☐	☐	☐	☐
I can avoid feeling discouraged	☐	☐	☐	☐	☐
I can bounce back from disappointment	☐	☐	☐	☐	☐
I can manage my symptoms during my daily activities	☐	☐	☐	☐	☐
I can keep my symptoms from interfering with relationships with friends and family	☐	☐	☐	☐	☐
I can manage my symptoms in a public place	☐	☐	☐	☐	☐
I can work with my doctor to manage my symptoms	☐	☐	☐	☐	☐
Joint Pain Muscle pain is common and difficult for people living with myositis to manage. The following questions are not about muscle pain but specifically ask about joint pain (shoulder, elbow, wrist, hip, knee, ankle, etc) which is less understood in myositis. Please answer the following questions specifically thinking about the pain that you attribute to your joints and not from other sources such as your nerves or muscles.					
Where is your joint pain located (select all that apply)? ☐ Shoulder ☐ Elbow ☐ Wrist ☐ Hand					

- ☐ Hip
- ☐ Knee
- ☐ Ankle
- ☐ Foot
- ☐ Neck
- ☐ Lower back
- ☐ Other
- ☐ None of the above

Which side is involved?

- ☐ Left
- ☐ Right
- ☐ Both
- ☐ Neither

How long have you had symptoms of your joint pain?

- ☐ 1-4 weeks
- ☐ 1-5 months
- ☐ 6-12 months
- ☐ 1-2 years
- ☐ 3-4 years
- ☐ >5 years
- ☐ Not applicable

On a scale of 1-10 with 1 being minimal and 10 being severe, what is your joint pain level?

- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ 6
- ☐ 7
- ☐ 8
- ☐ 9
- ☐ 10

Has your joint pain recently worsened?

- ☐ Yes
- ☐ No

Is your overall function declining due to joint pain?

- ☐ Yes
- ☐ No

Can you tolerate physical therapy exercises?

- ☐ Never
- ☐ Rarely
- ☐ Often
- ☐ Always
- ☐ I currently don't have PT

Do you use pain medication?

- ☐ Yes
- ☐ No

Orthopedic/Bone Issues: The following section is to assess mobility needs in myositis patients. By understanding the holistic burden of myositis in patients, including mobility needs and pain experiences as well, healthcare providers can better care for myositis patients.

Have you seen an orthopedic surgeon for any of your care related to myositis?

- ☐ Yes
☐ No

How many falls or orthopedic injuries have you had over the past year?

- ☐ 0
☐ 1
☐ 2
☐ 3
☐ 4
☐ 5 or more

How many falls have you had since your diagnosis of myositis?

- ☐ 0
☐ 1
☐ 2
☐ 3
☐ 4
☐ 5 or more

Do you use mobility aids (such as walking sticks, canes, crutches, walker, wheelchair)?

- ☐ Yes
☐ No

Do you use any braces or splints?

- ☐ Yes
☐ No

If you were on steroids for greater than 1 month, were you started on medications like vitamin D, calcium, and/or other osteoporosis medications to prevent fractures?

- ☐ Yes
☐ No

Have you had a fracture since you have been diagnosed with myositis?

- ☐ Yes
☐ No

Have you noticed any difficulty with using your arms or hands for activities of daily living?

- ☐ Yes
☐ No

How would you rate your upper extremity function compared to a completely normal upper extremity?

- ☐ 0-10%
- ☐ 11-20%
- ☐ 21-30%
- ☐ 31-40%
- ☐ 41-50%
- ☐ 51-60%
- ☐ 61-70%
- ☐ 71-80%
- ☐ 81-90%
- ☐ 91-100%

If you have Inclusion Body Myositis (IBM), would you consider hand surgery to temporarily improve hand function? Tendon transfer surgery in IBM uses redundant strong muscles to assist with weak muscles to improve grip and pinch strength (hold objects like a fork, button clothes, etc). The risks specific to IBM include the possibility of stiffness and that the surgery's potential benefits will decrease over time due to progressive weakness from IBM.

- ☐ Yes
- ☐ No
- ☐ I do not have IBM (Inclusion Body Myositis)

The 10 questions of the Patient-Reported Outcomes Measurement Information System-Physical Function (PROMIS-PF) Short Form 10a v2.0 tool (not shown) were also included in the questionnaire. The PROMIS-PF can be accessed at <https://www.healthmeasures.net/index.php>.

Table S1. Additional Patient Clinical Characteristics

Characteristic	Total respondents (N)	Responses
Time to diagnosis, years, mean (SD)	441	4.0 (5.9)
Presence of joint pain, n (%)	469	387 (82.5)
Use of pain medications, n (%)	459	195 (42.5)
Diagnostic method, n (%)	470	
Muscle biopsy		327 (69.6)
Antibody		171 (36.4)
Muscle MRI		92 (19.6)
Other		69 (14.7)
Skin biopsy		62 (13.2)
Response to treatment		47 (10.0)
None of the above		7 (1.5)

MRI, magnetic resonance imaging; SD, standard deviation.