WE CARE FOR RARE

Does Over-Reliance on Manual Muscle Testing (MMT8) in Myositis Diseases Commonly Negate Patient Voice?

Does this Cause Treatment Delays Leading to Long-Term Disability?

Ingrid de Groot, Lia Kolsters, Marie-Christine Breeveld, Karen Norris,
Karen Cheng, Helene Alexanderson, Lesley Ann Saketkoo on behalf of ***MIHRA Heavy Lifters***

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NORI'S
FIGHT

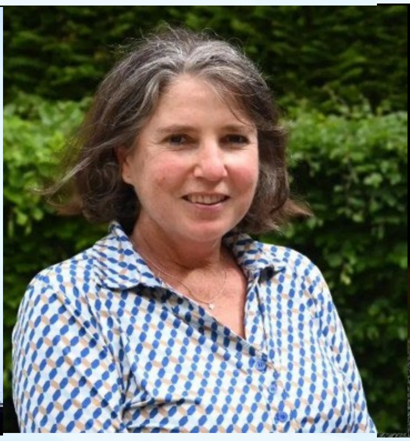
Coincidence of Perceptions
>> MIHRA Heavy Lifters!

Marie-Christine Breeveld

IBM

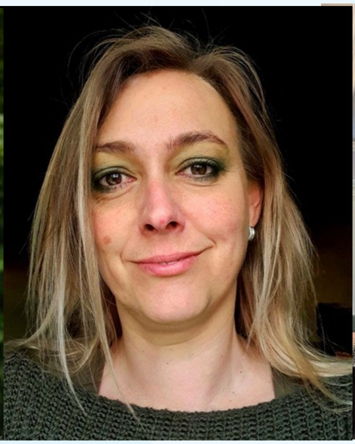
Karen Cheng

IMNM SRP+



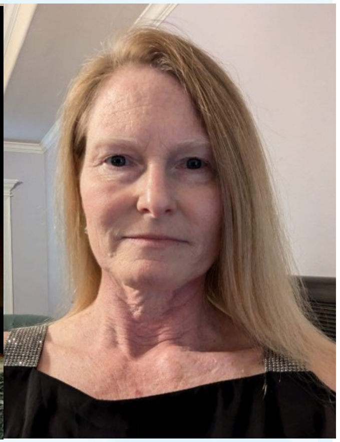
Ingrid de Groot

DM



Lia Kolsters

ASyS



Karen Norris

ASyS

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Four Major Strategic Areas

1. Consider the Existing Evidence regarding Patient Relevant Measures
2. Actions to understand Wider Patient Experience
3. Provide Immediate Patient-Relevant Guidance for Clinicians
4. Consider How the Patient Community Can Support Research Efforts in this Area

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1. The Literature We Scoped Revealed the Following:

1. Reliability Issues related to MMT8
2. Functional Index 3 (FI-3): more sensitive for detection, granular measures and better objectivity than MMT8
3. Muscle impairment may not necessarily mean active disease.
4. However active muscle disease may be suggested by:
    a. Shorter Disease Duration
    b. Progressive Impairment
    c. Flares
    d. or Active Disease in Other Organs
5. There is no standard skin assessment yet for myositis -related disease activity.
6. Currently no accepted scale exists for patient experience of skin or muscle

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2. Possible ways to investigate wider patient experience:

1. Initiate **open-ended** surveys to elicit **experience,**
2. Surveys to quantify this experience
3. **Share results** with patient and investigator communities

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3. Our Discoveries Prompted Us To Compile:

Two Preliminary Guides for Clinicians to integrate patient reported experience & to prevent treatment delay

for **immediate consideration**:

1. Diagnostic Guide for the Likelihood of Active Disease
2. Guide for Shared Decision-Making in Treatment Decisions

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Guide for Clinicians to Recognize the Likelihood of Active Muscle Disease When Traditional Measures are Indeterminate

Are there any muscle symptoms suggestive of inflammation, like pain, burning, tightness, tenderness to touch, decreased muscle endurance, or aching not made better by rest.

Is myositis of recent onset? Or has a “flare” occurred recently?

Is there progression?

Slow or rapid in the patient’s opinion are both valid rates of perceived loss.

Though diagnostics suggest low or no activity, is there a chance the patient's symptoms are related to treatable active disease and reversible inflammation?

Is there another organ that seems to have active disease, e.g. skin, lungs, leading to reasonable conclusion muscle may also be active?

Have the patient’s symptoms been itemized? With each symptom, queried if better, same or worse?

Has there been DMARD medication switching rather than attempts to reasonably add-on medications?

Prolonged or high dose use of steroids? Is steroid myopathy a possibility? Have steroids been tapered too quickly without other sufficient immunnosuppressive therapy?

Have the most relevant functional activities been itemized and queried if better, same or worse?

RARE DISEASE DAY
FEBRUARY 28, 2025

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Take a listening attitude & accounting of concerns from the patient side.

Discuss the risks & benefits of a trial period of a new / additional medication & reach a decision together.

Re-state patient concerns, so they know they have been heard.

Express understanding and belief in the patient report, even if traditional measures are not confirmative.

Recognize patient expressions are likely true, & diagnostics are often flawed in many diseases.

Log & track itemized symptoms. Be able to discuss trends with patients

Ask patients!!

In addition to clinician opinion, patients may have ideas on what next steps & ideas for following response!

Explain the likelihood of active muscle disease versus that of irreversible damage.

Ongoing muscle inflammation leads to irreversible damage & long-term disability, if uncertain, consider adding a DMARD & use patient symptoms as metric to check response.

Explain to patient that without objective measures, the patient's itemized symptoms & reported function will be used as metrics.

Guide for Shared Decision-Making (SDM) to Help Prevent Delayed Treatment of Active Muscle Disease

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4. Get Patients Involved in Improving Clinical Assessment in IIMs!

https://mihrafoundation.org/mihra-patient-contact-registry/

Patient partners be involved in study design & development

Be Available to Support:

- Participate in surveys & focus groups
- Test and Provide Feedback on:
    - questionnaires for investigators
    - apps for new measures
- Join the MIHRA Patient Contact Registry

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Thank You!!

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