



The start of our new webinar series, "**Managing Your Care Starts With You**" with Medical Advisor, Dr. Salman Bhai, launching for Myositis Awareness Month!

Join us for the first episode . . .

## Communicating with your doctor as a Myositis patient

Wednesday, May 12, 7 PM ET

**SALMAN BHAI, M.D.**

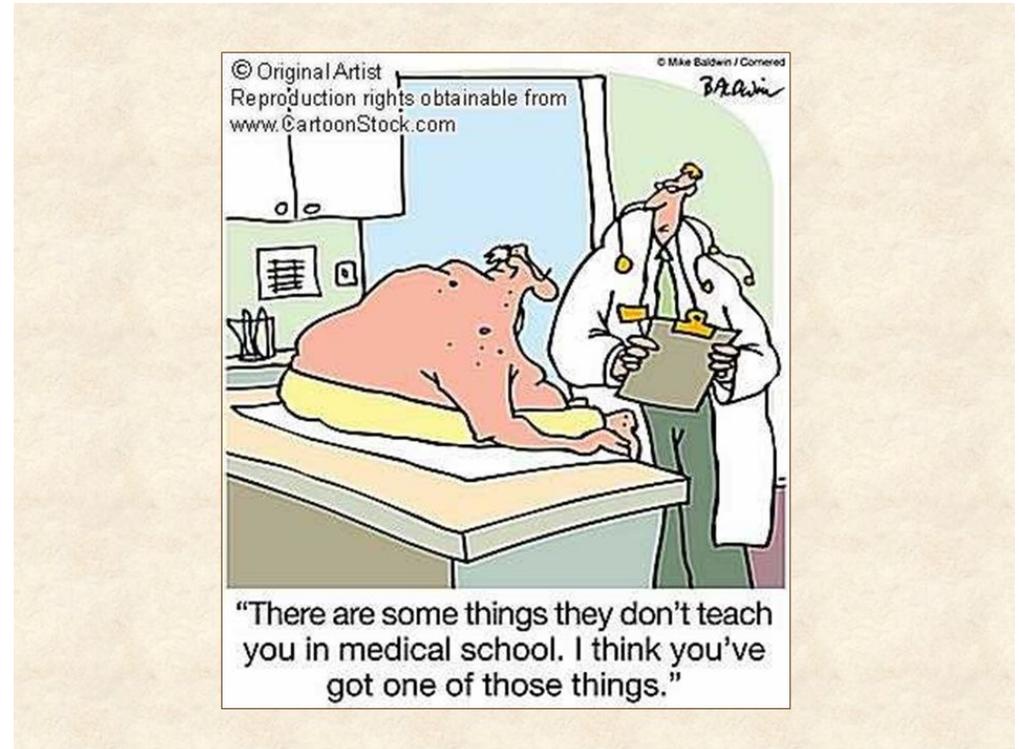
*Neurologist, UT Southwestern Medical Center,  
Institute of Exercise and Environmental Medicine*

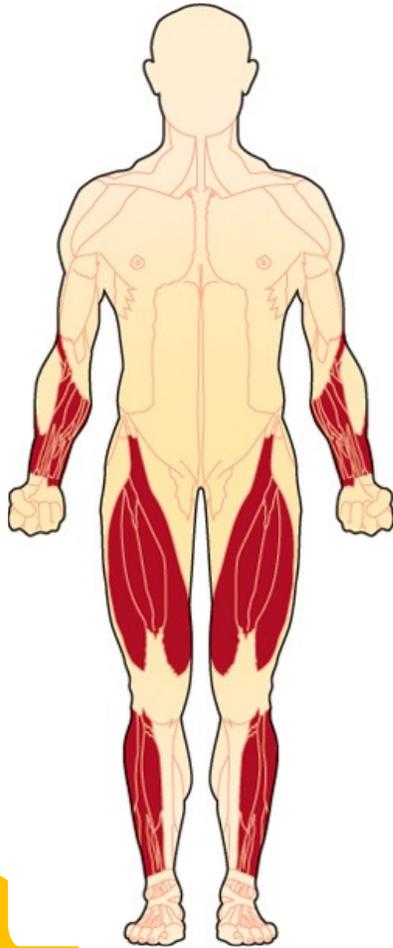
[Understandingmyositis.org/events](https://Understandingmyositis.org/events)



# Patient-Doctor Relationship

- What are your goals?
- What is not or has not been addressed?
- What are your concerns or hesitations?
- Who is your team? Your healthcare team? Your support?
- Multidisciplinary care is key
- Tele-health is making visits easier ... and harder





# Myositis is a team effort

- Start with yourself: psychological support and self-care
- Caregiver support: physical, emotional, and mental health
- Financial barriers: work with advocacy groups, HCP team, social workers, and your insurance
- Outside of clinic: physical and occupational therapy, speech and language pathology, social work, nutrition
- Clinic team: physicians, nurses, NPs, PAs, students, trainees
- Beyond: advocacy groups and research

# Holistic treatment begins with you

Medications are important and necessary

Complementary practices

- Healthy diet
- Sun protection
- Exercise for your mind and body
- Mindfulness practices

Be open with your team about your needs

# Guide research



**What is most important for you to see change in your disease?**

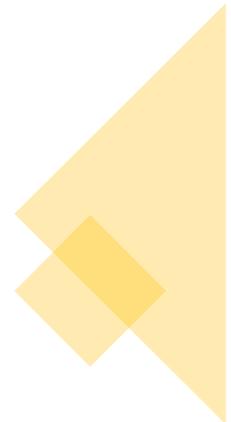
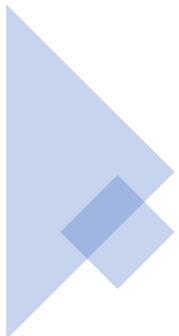


**What parts of your disease are not addressed?**



**Participate!**

Biobank for basic and translational science  
Epidemiologic studies  
Clinical trials  
Focus groups



# Question & Answers

- We will start with the Q&A from webinar registration
- Time permitting, Dr. Bhai will address additional questions.
  - Locate the Q&A icon in your Zoom toolbar and enter your question

# Patient & Doctor Relationships

- Any tips for better supporting/establishing expectations in re: the primary care-specialist interface, chronic condition care management, continuity/coordination of care, etc.? (CADM)
- I have had a new rheumatologist for a year now. He doesn't seem want to hear my questions/comments. It feels like he "knows it all ". My old doctor was great. I was diagnosed in 2003 with DM. How do I reach him?
- I was diagnosed with ASS syndrome 6 years ago. I would have liked my doctor to have shared physical exercises and dietary suggestions, also would have liked to informed me of resources online which would have added to my understanding, including the MSU website and support groups

# Patient & Doctor Relationships

- How to discuss pain management for myositis given the concerns with opioids by doctors? (DM)
- What words to use to help my doctor to do better and more accurate muscle strength tests that will help them see our true function day to day with Activities of Daily Living ? Do we insist that they do the same test multiple times to see how weak we get? (DM)
- How can your doctor help to determine if you should stop working a full time job, and steps to obtain company sponsored LTD insurance and/or social security disability insurance (SSDI) coverage? (IBM)

# Patient & Doctor Relationships

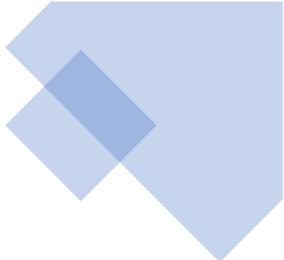
- Coordinating care between different health care organizations has been more than challenging. An ER experience where none of the doctors has heard of IBM and did not bother to contact my neurologist, after I provided all contact information, left me shaken and deeply disturbed about their lack of knowledge regarding appropriate care for me--and their lack of listening skills as well, preferring to talk to someone else in the room as though I didn't exist. I changed medical groups on the spot, not easy, but I did it. What else can I do?
- How often should I see a neurologist, and what do I need to discuss with him or her? (IBM)

# Diagnosis & Treatments

- I've seen two neuromuscular specialists, but do not have a diagnosis. I've tested positive for anti-NT5C1A when I saw the first doctor, but he moved out of state. The second specialist I saw was sure I don't have IBM. All other labs negative. First biopsy was not conclusive. Have had EMG and MRI. Am now experiencing more symptoms but don't feel heard by the latest doctor. I'm asking to see another specialist. It's been 6 years since first and I feel discouraged and disheartened.

# Diagnosis & Treatments

- Living with Calcinosis for 33 years, Dx as Juvenile DM, it has been a struggle with Raynaud's and systemic vasculitis as well, it covers 90% of my body, what are the new treatments?
- What else can I do when I've received high dose of prednisone, Imuran, IVIG, Rituxan, Cytoxan, Abatacept trial with no improvement. Recently lost my ability to get up from lift chair & walk. This is my 6th year in the battle. What else should I do? (IMNM)
- I have a lot of hair loss, down the middle of the hairline. Almost bald. What is causing this? Taking methotrexate and prednisone. Is that too much? (PM)
- Is there anything encouraging for IBM?



## Managing Your Care Starts With You A New Webinar Series

Join us in welcoming Dr. Bhai for a New Series called – **Managing Your Care Starts With You**, a webinar series that over the coming months will explore how doctors today are taking a patient-centered approach to managing the care of our diverse myositis community. We hear a lot about patient-centered care, patient-centered research, patient-centered outcomes, but what does it really mean for the myositis community, for research and drug development, and for your care?

Ideas? Send you ideas to  
[info@understandingmyositis.org](mailto:info@understandingmyositis.org) or  
[lynn@understandingmyositis.org](mailto:lynn@understandingmyositis.org)

- **When You are at Risk** – Care strategies on different topics -cancer screening, dysphagia, ILD, emotional health, underserved myositis communities
  - **Managing Your Care Team**
  - **Living Alone, Living Independently**
  - **The Rollercoaster of Flares**
  - **The Pain is Real** – a review of MSU’s 2019 survey of over 450 patients on Pain and Opioids, what current research is telling us about pain, and current thinking on treating pain, real-life strategies
  - **The Alphabet Soup of Myositis Antibodies** – what are they and what do they tell us about managing our care
- 