Anti-MDA5 DM

Hello! I’m Benita Moyers.

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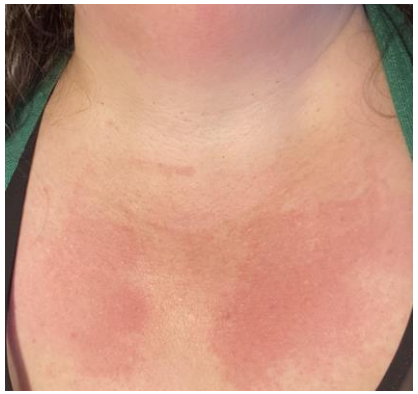
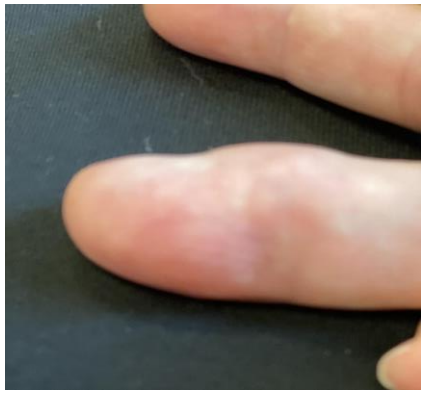
Anti-MDA5 DM Diagnosis Journey

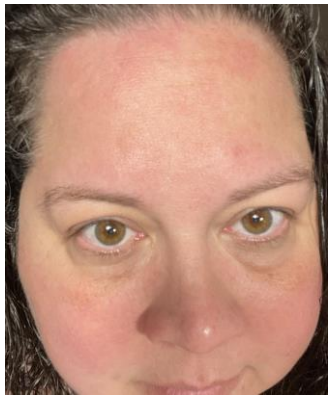


V-Neck Rash

- Muscle fatigue and pain / Joint pain / Weak grip
- Pneumonia, low oxygen, & breathing options.
- Rashes on face, neck, chest, and hands.
- Sun sensitivity
- Calcinosis in finger
- Dysphagia, voice changes, requiring speech therapy.

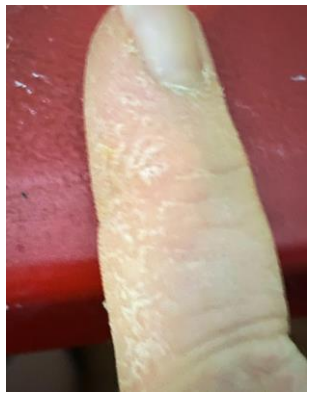
Calcinosis





Facial Rashes

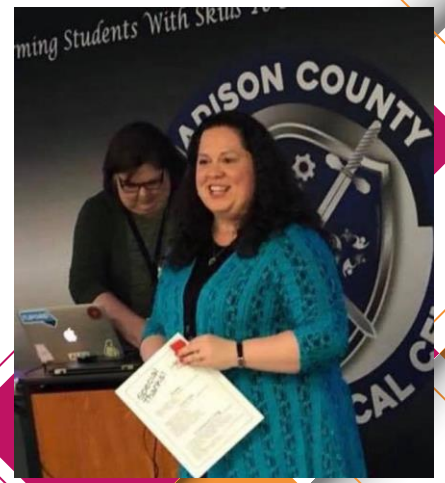
Palmar Rash



Mechanic's Hands

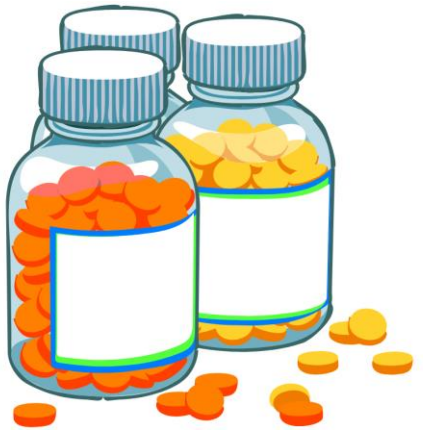
Life Changes with MDA5 DM

- Retired from teaching on disability
- Stopped speaking and training for Google and state and national education groups.
- Resigned from a multiple boards due to inability to travel.



Major Life Changes with MDA5 DM

- Accommodations around the house
  - Dishes, pots, and pans down lower
  - Handles in bathroom shower
  - Lift chair
  - Grippers and openers
- IVIG infusions every other week.
- Three immune suppression meds.
- Two heart meds, pain meds, ointments, and more meds...meds...meds
- Magnesium, B12, Vitamin D for deficiencies.



Therapies for Quality of Life

- Physical therapy for muscles, balance, etc.
- Occupational therapy for hands and lymphedema
- Daily compression therapy for lymphedema and pain
- Speech therapy for dysphagia and vocal chord issues
- Breather for lungs
- Acrylic painting, crochet, diamond painting to rebuild fine motor skills and grip strength

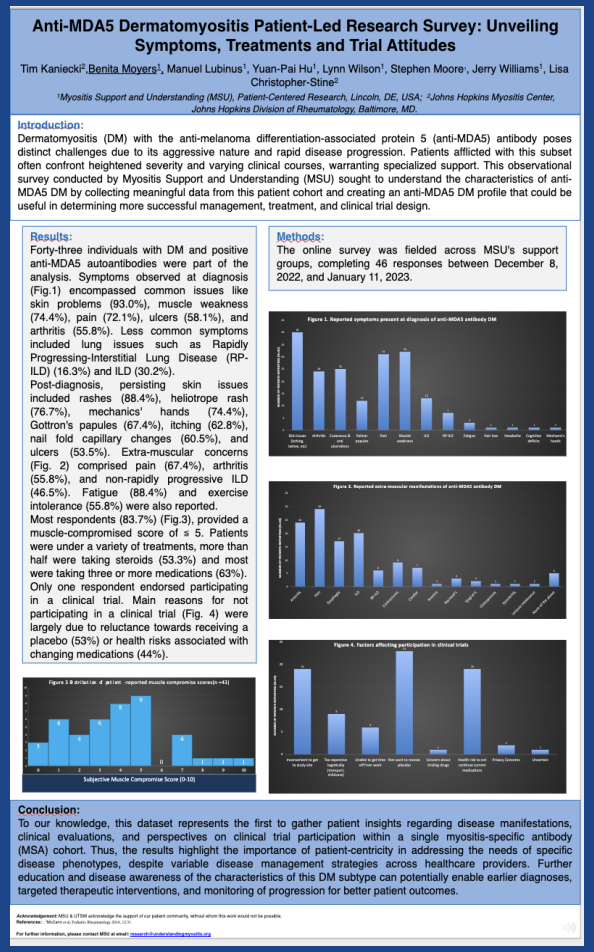
Finding a New Purpose

- Started a private Facebook group for MDA5 patients.
  - Over 400 members
- Volunteer with Myositis Support & Understanding
  - Support groups, patient research, board
  - MDA5 Patient survey
- **Keep fighting DM and advocating for a cure!**

Thank you!

For questions, please email me or visit the Myositis Support and Understanding table and our Anti-MDA5 abstract poster.

benita@understandingmyositis.org



Anti-MDA5 Dermatomyositis Patient-Led Research Survey: Unveiling Symptoms, Treatments and Trial Attitudes

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Introduction:
Dermatomyositis (DM) with the anti-melanoma differentiation-associated protein 5 (anti-MDA5) antibody poses distinct challenges due to its aggressive nature and rapid disease progression. Patients afflicted with this subset often confront heightened severity and varying clinical courses, warranting specialized support. This observational survey conducted by Myositis Support and Understanding (MSU) sought to understand the characteristics of anti-MDA5 DM by collecting meaningful data from this patient cohort and creating an anti-MDA5 DM profile that could be useful in determining more successful management, treatment, and clinical trial design.

Results:
Forty-three individuals with DM and positive anti-MDA5 autoantibodies were part of the analysis. Symptoms observed at diagnosis (Fig.1) encompassed common issues like skin problems (93.0%), muscle weakness (74.4%), pain (72.1%), ulcers (58.1%), and arthritis (55.8%). Less common symptoms included lung issues such as Rapidly Progressing-Interstitial Lung Disease (RP-ILD) (16.3%) and ILD (30.2%).
Post-diagnosis, persisting skin issues included rashes (88.4%), heliotrope rash (76.7%), mechanics' hands (74.4%), Gottron's papules (67.4%), itching (62.8%), nail fold capillary changes (60.5%), and ulcers (53.5%). Extra-muscular concerns (Fig. 2) comprised pain (67.4%), arthritis (55.8%), and non-rapidly progressive ILD (46.5%). Fatigue (88.4%) and exercise intolerance (55.8%) were also reported.
Most respondents (83.7%) (Fig.3), provided a muscle-compromised score of ≥ 5. Patients were under a variety of treatments, more than half were taking steroids (53.3%) and most were taking three or more medications (63%). Only one respondent endorsed participating in a clinical trial. Main reasons for not participating in a clinical trial (Fig. 4) were largely due to reluctance towards receiving a placebo (53%) or health risks associated with changing medications (44%).

Methods:
The online survey was fielded across MSU's support groups, completing 46 responses between December 8, 2022, and January 11, 2023.

Conclusion:
To our knowledge, this dataset represents the first to gather patient insights regarding disease manifestations, clinical evaluations, and perspectives on clinical trial participation within a single myositis-specific antibody (MSA) cohort. Thus, the results highlight the importance of patient-centricity in addressing the needs of specific disease phenotypes, despite variable disease management strategies across healthcare providers. Further education and disease awareness of the characteristics of this DM subtype can potentially enable earlier diagnoses, targeted therapeutic interventions, and monitoring of progression for better patient outcomes.

Acknowledgement: MSU & UTSW acknowledge the support of our patient community, without whom this work would not be possible.
References: McCann et al, Pediatric Rheumatology 2014, 12:31
For further information, please contact MSU at email: research@understandingmyositis.org