

# PATIENT IMPACT ON MYOSITIS RESEARCH

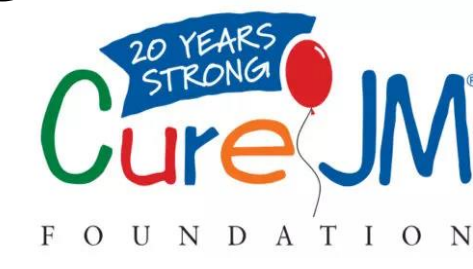
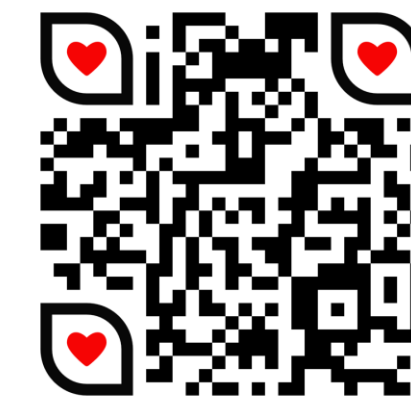


## Introduction:

Patients and patient organizations play a pivotal role in myositis research. Increasingly there are patients who are actively involved in academic research, national and international myositis research organizations and industry-sponsored patient advisory councils. The value of the real expert in myositis – the patient - is now gaining greater recognition, which allows for more patient-centric research, focusing on more relevant outcomes and improving the quality of life for patients living with myositis worldwide.

## HOW PATIENTS IMPACT RESEARCH

Recent Chan-Zuckerberg rare disease research grant awarded to Cure JM to identify new biomarkers and improve precise, personalized care through the identification of cell-to-cell interactions that drive inflammation in juvenile myositis.



Patient-centred research collaborations on myositis Patient Journey and Burden of Disease, including Caregiver Burden, Anti-MDA5 DM, and studies in Pain in Myositis<sup>1</sup> and Tendon Transfer Study<sup>2</sup> collaborations.



Patients initiated and contributed to a patient/carer priority study and contributed to a continence survey in Myositis study. Patients helped identify factors in diagnostic delays and helped to co-develop a toolkit to educate and assist primary care clinicians in diagnosing myositis<sup>4,5</sup>. Stay tuned for this toolkit which is coming!



Bringing the patient voice to the US FDA regulatory review processes via the Externally-led Patient-focused Drug Development (EL-PFDD) program.



Patients co-authored and contributed to the design, data analysis, publication and dissemination of results of international collaborations such as the COVAD study, OMERACT myositis working group, and IMACS Exercise and Rehabilitation study.

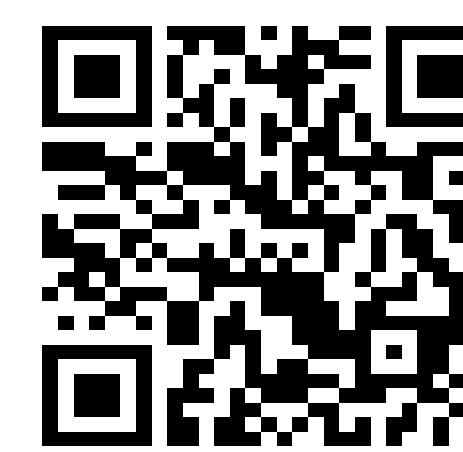
Patients help to review worldwide study grant applications.

Education of Patient Research Partners (PRP) & mentoring of new PRPs, PRP involvement in collaboration with researcher groups.

Involvement of PAOs in clinical trial patient enrollment, educational efforts and facilitating communication from and with sponsors.

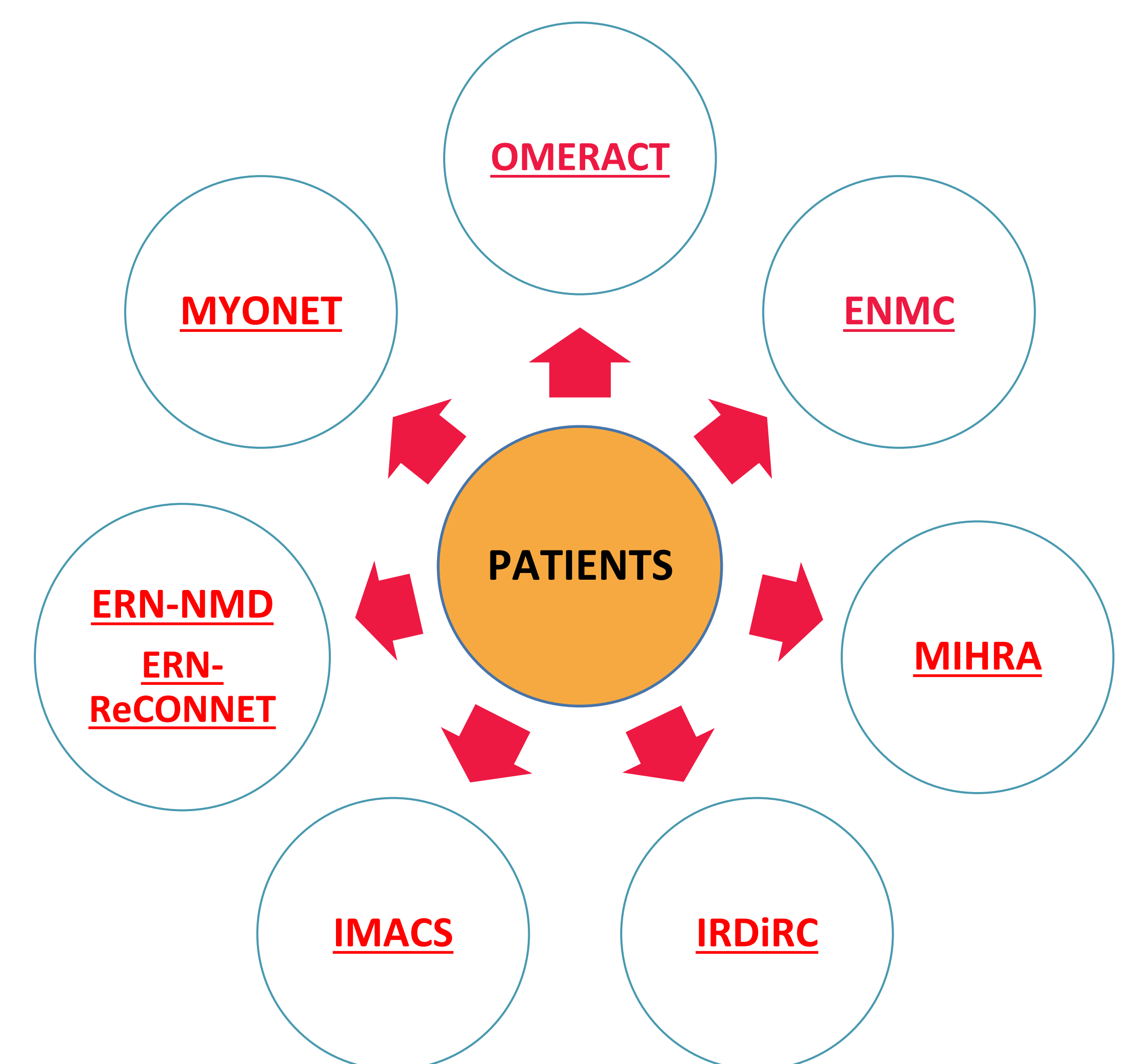
Patient coalitions are taking a more active role in advocating for policy changes to help advance research and drug development for myositis.

## Patient representatives' editorial



*Working towards a patient-centred Global Myositis Alliance: call for partnership<sup>3</sup> : Exploring goals, challenges, and opportunities for a researcher-patient community partnership.*

## Patients are part of international research working groups (click on links for more info)



\*IMACS Examples of working groups -Exercise & Rehabilitation group; Psychological impact & Wellbeing Group; IBM Special Interest Group

## Visibility



In addition, sites such as International Myositis Society **iMyos** offer the patient community a one-stop platform by listing information and contact details of patient organizations on their website.

## Further ways to improve patient collaboration in myositis research

**Ensure patients have a seat** on advisory boards and research roundtables in order to bring real patient perspectives to the discussion ( eg. patient organization advisory boards, pharmaceutical clinical development, and medical advisory boards).

**Always include patient input** in collaborations with groups such as the **NIH** and **PCORI** which provide research grants.

Establish an **international myositis research patient & consumer panel** to support better understanding of patient needs.

Patients to help **develop national research agendas** in countries around the globe.

**Call to action on World Myositis Day September 21:** Opportunities to highlight more patient impact on research!



### References:

<sup>1</sup>Bhaskiyam A, Lubinus M, Filmore E, Wilson L, Williams J, Gonzalez Ramos O, Bhal S. Pain profile and opioid medication use in patients with idiopathic inflammatory myopathies. *Rheumatology (Oxford)* 2022; Dec 23;62(11):264-269. doi: 10.1093/rheumatology/keac271. PMID: 35579332; PMCID: PMC9788817.  
<sup>2</sup>Hua C, Bhal S, Cheng J, Hinojosa J, Wilson L, Lubinus M, Bhaskiyam AR. Tendon Transfers to Improve Grasp and Pinch in Patients with Sporadic Inclusion Body Myositis. *Plast Reconstr Surg Glob Open*. 2023 Nov 17;11(11):e5418. doi: 10.1097/GOX.0000000000005418. PMID: 38025613; PMCID: PMC10656093.  
<sup>3</sup>Schiller S, de Groot I, Lubinus M, Dihkan A, Johansson J, Drápalová O, Oakley I. Working towards a patient-centred Global Myositis Alliance: call for partnership. *Clin Exp Rheumatol*. 2023 Mar;41(2):214-216. doi: 10.55563/clinexp/rheumatol/u1pdm. Epub 2023 Jan 11. PMID: 36700650.  
<sup>4</sup>Namsrai T, Desborough J, Chalmers A, Lowe C, Cook M, Phillips C, Parkinson A. *BMJ Open*. 2022 Jun 13;12(6):e060312. doi: 10.1136/bmjopen-2021-060312. PMID: 35697457.  
<sup>5</sup>Namsrai T, Desborough J, Chalmers A, Lowe C, Cook M, Phillips C, Parkinson A. Diagnostic delay of myositis: protocol for an integrated systematic review. *BMJ Open*. 2022 Jun 13;12(6):e060312. doi: 10.1136/bmjopen-2021-060312. PMID: 35697457; PMCID: PMC9196154.  
MDA5 DM: Anti-melanoma differentiation-associated gene 5 (MDA5) Dermatomyositis