Editorial

Shared governance of international myositis networks

T. Liewluck[1], L.G. Rider[2], K. Cheng[3,4], H. Chinoy[5,6], M.M. Dimachkie[7], E. Dourado[8-10], P.C. Gandiga[11], D.A. Isenberg[12], K. Ardalan[13], S. Keret[14], S. Kim[15], P. Korsten[16], I.E. Lundberg[17,18], P.M. Machado[19], F.W. Miller[2], C. Papadopoulou[20], S. Rosina[21], L.A. Saketkoo[22], S. Schlüter[23], J. Vencovský[24], A.J. van der Kooi[25], J. Schmidt[26,27]

Affiliations: page 183.

Teerin Liewluck, iMyoS
Lisa G. Rider, IMACS
Karen Cheng, iMyoS, PAO
Hector Chinoy, MYONET
Mazen M. Dimachkie, IMACS
Eduardo Dourado, MCTC
Prateek C. Gandiga, MCTC
David A. Isenberg, IMACS
Kaveh Ardalan, CARRA JDM
Shiri Keret, MCTC
Susan Kim, CARRA JDM
Peter Korsten, iMyoS
Ingrid E. Lundberg, MYONET
Pedro M. Machado, MIHRA
Frederick W. Miller, IMACS
Charalampia Papadopoulou, PReS JDM
Silvia Rosina, PReS JDM
Lesley Ann Saketkoo, MIHRA
Silke Schlüter, iMyoS, PAO
Jiri Vencovský, MYONET
Anneke J. van der Kooi, iMyoS
Jens Schmidt, iMyoS

Networks in myositis as represented in the governance group:
PAO: Patient Advocacy Organizations
MCTC: Myositis Clinical Trials Consortium
IMACS: International Myositis Assessment and Clinical Studies Group
iMyoS: International Myositis Society
MYONET: Global Myositis Network
MIHRA: Myositis International Health and Research Collaborative Alliance
CARRA JDM: Childhood Arthritis and Rheumatology Research Alliance Juvenile Dermatomyositis
PReS: Paediatric Rheumatology European Society
PReS JDM: Paediatric Rheumatology European Society-Juvenile Dermatomyositis

Please address correspondence to:
Jens Schmidt
International Myositis Society (iMyoS), c/o Department of Neurology, University Medical Center Göttingen, Robert-Koch-Str. 40, 37075 Göttingen, Germany.
E-mail: j.schmidt@gmx.org

Received on October 1, 2025; accepted in revised form on January 28, 2026.
Clin Exp Rheumatol 2026; 44: 178-185.

Funding and competing interests: page 184.

Introduction

The field of myositis has witnessed remarkable progress in recent decades with advances in disease classification, outcome measures, clinical trials, and therapeutic options. Yet progress has often been hampered by fragmented parallel efforts across countries, inconsistent definitions, and limited opportunities for collaborative dialogue and true alignment. Effective governance is essential to overcome this obstacle. In this context, governance refers to the structures, processes, and leadership that allow the myositis community to collectively agree on setting global priorities, coordinating research and care, and ensuring accountability, inclusivity, and transparency across all initiatives.

Several international initiatives have already emerged as pillars of governance. The International Myositis Society (iMyoS) provides a global forum for multi-disciplinary scientific exchange and leadership. The International Myositis Assessment and Clinical Studies Group (IMACS) and the Myositis Clinical Trials Consortium (MCTC) have been instrumental in developing outcome measures and advancing therapeutic trials. MYONET (Global Myositis Network) is responsible for the largest inflammatory myopathy registry in the world, and Myositis International Health and Research Collaborative Alliance (MIHRA) contribute through collaborative networks and research alliances, while paediatric and adolescent care is advanced through groups such as the Childhood Arthritis and Rheumatology Research Alliance-Juvenile Dermatomyositis (CARRA JDM) and the Paediatric Rheumatology European Society-Juvenile Dermatomyositis (PReS JDM). Together, these organisations provide the scaffolding for building and coordinating governance that can unify efforts across the globe. By fostering stronger connections among these groups and embracing governance as a shared responsibility, the myositis community is poised to accelerate discovery, harmonise care, and ultimately transform the lives of myositis patients worldwide.

Contributions of patient organisations are vital elements of the myositis governance by providing invaluable insights, advocacy, partnership, and lived experience to shape many of the advances in the field (1). Their role and engagement remain an essential pillar of effective governance in myositis to support scientific progress and innovation to improve patient outcomes. This editorial will focus on the missions and contributions of the principal international research and clinical networks that are advancing governance in myositis (Fig. 1).

International Myositis Society (iMyoS)

The International Myositis Society (iMyoS) was established in 2019, after detailed planning within the global myositis community (2). Myositis is a heterogeneous and debilitating group of diseases that demand multidisciplinary care, highlighting the critical importance of coordinated efforts and collaboration across specialties and professional societies. iMyoS was created to help provide a global infrastructure to harmonise standards of care, diagnostic criteria, and classification systems, and by fostering collaboration among neurologists, rheumatologists, dermatologists, paediatricians, pulmonologists, and other stakeholders from all over the world. Today, the society brings together 198 members from 28

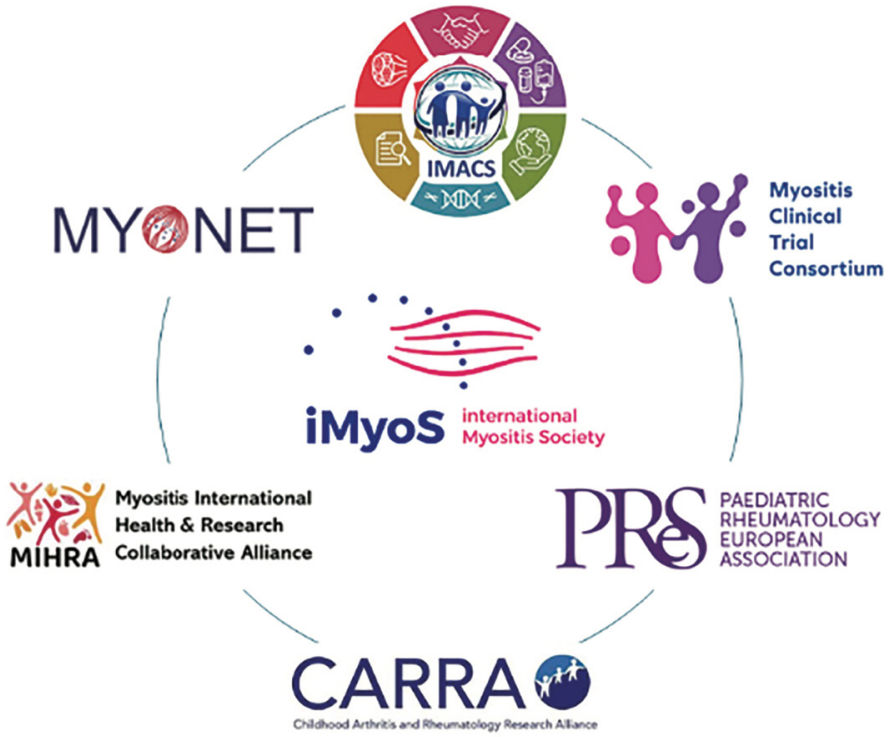

Fig. 1. Governance structure of international myositis networks.
Schematic representation of the organisational framework that underpins international myositis governance.

countries, reflecting its broad international reach and commitment to unifying the global myositis community.

The Society's primary mission is to support the development and harmonisation of diagnostic criteria and standards of care and to ensure their implementation across major international and national societies; to foster the education of myositis specialists by promoting interdisciplinary curricula, creating fellowship opportunities, and encouraging the integration of myositis training into broader neurology, rheumatology and immunology programs; to increase international awareness of myositis; to promote and facilitate research funding; and to strengthen collaborations with existing networks such as IMACS, MCTC, MIHRA, MYONET, Euromyositis, CARRA JDM, and PReS JDM. Patient representatives in iMyoS also help to bring the collective voice of patient organisations across the world to many initiatives organised by these networks. Another important role of iMyoS is hosting of the GCOM meetings, the premier meetings on myositis that are held every two years. In addition, iMyoS has partnered with *Clinical and Experimental Rheumatology* as its home journal to host consensus papers, guidelines, and reviews, including an annual thematic issue on myositis. By acting as an umbrella organisation, iMyoS seeks not to replace existing efforts but to unify and amplify them, thereby improving patient care and advancing research worldwide.

Since its inception, iMyoS has already contributed meaningfully to the field. It has provided organisational support and scientific leadership for recent GCOM meetings, ensuring continuity and high-quality programming that integrates both adult and paediatric myositis research. The Society has initiated efforts to harmonise classification and diagnostic criteria, building on prior consensus work and promoting their adoption across different regions. This is reflected in a recent editorial that emphasised the need for globally unified and clinically relevant criteria, highlighted the limitations of the 2017 EULAR/ACR criteria, and proposed updates to better incorporate newer autoantibodies, overlap syndromes, and extra-muscular features (3). These early achievements illustrate how iMyoS has rapidly become a driver of governance and global coordination in myositis.

iMyoS website provides a joint home for all myositis networks as well as for the patient association organisations from all over the world (www.imyos.org). This website has recently been upgraded to host a global calendar for myositis events to improve visibility across organisations worldwide. All networks can list their local, regional, national or global scientific, clinical and educational activities, regardless if the events will be on-site, virtual or in a hybrid format.

International Myositis Assessment and Clinical Studies Group (IMACS)

The International Myositis Assessment and Clinical Studies Group (IMACS) is an international multidisciplinary consortium of myositis clinical and basic researchers, allied health professionals, patient leaders, and industry representatives consisting of over 970 members from 60 countries. IMACS members share a common interest of advancing our understanding of the causes of myositis and improving patient lives through the development of new assessments and therapies. IMACS has worked for the past 25 years to achieve these goals through consensus and data-driven methodologies, in developing core set measures of myositis disease activity and damage, response criteria to determine clinically meaningful improvement in disease activity, and consensus guidelines in the conduct of myositis clinical trials (4). Members of IMACS lead investigator-initiated collaborative research projects with use of the consortium for contributions of data, surveys and consensus. Projects also emanate from the ten Scientific Interest Groups (SIGs), which focus on important topics in the field and meet several times annually. Recently completed projects among more than 40 ongoing studies have included contributions to the EULAR-ACR classification criteria for idiopathic inflammatory myopathies (IIMs), genome-wide association studies to identify novel genetic risk factors, development of cancer screening guidelines for pa-

tients with dermatomyositis, and systematic literature reviews of myositis autoantibody assay methodologies and magnetic resonance imaging in the evaluation of adult and juvenile myositis (5, 6). IMACS has recently developed standardised coding of key myositis assessment tools and criteria that will be deposited in the NIH Common Data Elements (CDE) public repository, and also be made available through release of data dictionaries and study forms using REDCap, a database used at many universities. This should further standardise data collection and sharing among centres and databases. IMACS also hosts a database of myositis databases in which 76 databases are registered, to promote collaboration among investigators.

IMACS has led annual meetings in which members share project and SIG updates but also discuss controversial and unresolved topics that often lead to new projects. The meeting committee plans the annual meeting and also leads an annual newsletter to update members on IMACS scientific and other activities. The scientific committee reviews and approves research projects and manuscripts, providing critical feedback and ensuring appropriate use of the network. IMACS also has initiated a myositis mentoring program where fellows in training and junior faculty can be mentored by a more senior myositis researcher for up to two years. Broader mentorship meetings are also held in conjunction with the large subspecialty conferences and the GCOM. IMACS also hosts training materials, including slide sets and videos, for many of the core outcome assessment tools; training certificates are issued to members upon completion of each module.

IMACS was the first global organisation that catalysed heightened interest in myositis and the creation of additional international groups focused on research, care and education in myositis. IMACS is committed to collaborate synergistically with myositis focused organisations in order to advance the field. For many years, IMACS co-hosted its annual meeting with the paediatric groups CARRA and PReS Working Group and shared several projects, and also actively collaborated in the development of core set measures and response criteria with the PRINTO group. In 2025, IMACS transformed the scope of its in-person annual meeting to a myositis consortium meeting to involve all of the myositis groups that are part of the governance to present their work to promote collaboration and augment expertise among groups and minimise duplication of efforts. Each group will present work on the podium and in a few posters.

Myositis Clinical Trials Consortium (MCTC)

The Myositis Clinical Trials Consortium (MCTC) is an international, interdisciplinary, non-profit alliance committed to advancing the global clinical trials landscape in autoimmune myositis, myositis-associated interstitial lung disease (ILD), and other associated conditions. Established to facilitate, support, and coordinate high-quality clinical trial initiatives and related research, the MCTC serves as a collaborative forum uniting investigators from diverse specialties, academic and community sites, myositis clinicians, patient partners, and industry collaborators to accelerate the development of evidence-based treatments for these rare diseases (7).

The MCTC's organisational structure is designed to ensure global representation and diverse leadership. Its membership has grown to over 960 individuals across more than 70 countries spanning six continents. At its core, strategic oversight is provided by a Steering Committee of senior investigators and stakeholder representatives (including rheumatologists, neurologists, dermatologists, pulmonologists, patient advocates and clinical trial professionals). A junior Core Group serves as the operational body, responsible for day-to-day activities such as member engagement, outreach, research initiatives, and partnerships with industry and patient support organisations. This dual leadership framework balances strategic guidance with operational flexibility, enabling efficient execution of the consortium's agenda while fostering mentorship and development opportunities for early-career professionals. The broader membership, encompassing clinicians, researchers, trial professionals, and emerging myositis centres, strengthens infrastructure and expands trial accessibility. Integral to this structure is collaboration with patient support organisations, ensuring that patient perspectives inform priorities, outcome measure development, and dissemination.

In 2025, the MCTC launched ten focused projects to address several identified high-priority critical gaps in the planning, conduct, and interpretation of myositis clinical trials, with results expected to be disseminated to the myositis community during 2025-2026. To ensure collaboration and early engagement with the paediatric myositis community, almost all projects include juvenile myositis investigations. In addition, the MCTC also engages with external partners including independent researchers, industry partners and patient support organisations on multiple joint initiatives to collectively cultivate advances in myositis clinical trials infrastructure, disease understanding, and treatment discovery.

Recognising the life-threatening nature of lung involvement, MCTC has established the IIM-ILD Working Group, a multidisciplinary team that aims to characterise and standardise the heterogeneity of myositis-related ILD and create a unified platform for research. This cohesive undertaking is dedicated to advancing clinical trial efforts in the early recognition, prevention, and treatment of myositis-related pulmonary complications. This initiative highlights MCTC's commitment to interdisciplinary collaboration, early engagement of the paediatric community, and comprehensive strategies to address myositis as a syndrome with diverse manifestations.

Looking ahead, the MCTC plans to broaden its global collaborative footprint, establish structured training programs in outcome assessments, promote clinical trial readiness and develop consensus-based guidance on trial methodology and operational standards. These initiatives will help establish new myositis investigators and clinical trial

centres while reinforcing a framework for equitable trial accessibility across diverse populations and geographic regions. Through a shared vision and collective effort, the MCTC is uniquely positioned to lead efforts in advancing the landscape of myositis clinical trials and accelerating the development of meaningful, evidence-based therapies for patients worldwide.

Global Myositis Network (MYONET)

MYONET (Global Myositis Network) is a joint initiative bringing together centres focusing on patients with IIMs, covering the epidemiological, clinical, pathogenic, genetic and therapeutic aspects of myositis. Cooperation within the field of myositis research developed as part of two prior European collaborative projects. An important factor was meetings at regular small symposia and workshops, which helped to address the tasks of these projects. These included investigating pathogenic processes and genetic predisposition to the disease. Completion of the projects required extensive collaboration on larger patient groups. This led to the creation of an international patient registry, which became the core activity of MYONET. The registry currently includes over 8,000 patients with at least 1 entry of information and over 3,000 patients who have more than one visit as part of longitudinal follow-up. Most of the patients are adults, but juvenile myositis is also included. The registry mainly includes European centres, but several Asian, American and Australian centres also participate. Continuous improvements are being made, most recently, for example, simplifying therapy monitoring and adding forms for registering the results of nail capillaroscopy, HRCT, and lung function tests. Work is underway to expand research capabilities based on OMOP and DataSHIELD, so that data can be analysed according to the OMOP standard without giving researchers access to any raw data. A link between the MYONET registry and the European Reference Networks for Rare Diseases registry is also in the development.

The basis of the registry is built on two parts: the first collects basic patient data, which provides the necessary information and is a mandatory part, and the second is an extended part, which is more detailed and includes repeated monitoring, including the use of tools to assess disease activity, patient damage, physical abilities, laboratory parameters, and therapy. Over the years, data from the registry has been used to investigate aspects of the disease such as disease progression prediction, autoantibody associations, biomarkers, cardiovascular consequences of systemic inflammation, links between clinical subtypes, extra-muscular involvement, environmental influences, and medication use, or comparisons of the manifestations of DM and ASyS, the association of autoantibodies with damage, or the activity of systemic inflammation and its impact on the patient's assessment of their condition. An extensive analysis is currently underway that will inform the long-term prognosis of patients with myositis, as well as an analysis of global patterns of IVIg prescribing in IIM.

MYONET plays a collaborative role within the governance structure where the platform can be used to collect and share data being collected by other iMyoS affiliated and external organisations. Following local ethics approval to collect data, members are obliged to complete a Data Sharing Agreement which allows sharing of registry data with other collaborators. Requests to access registry data should be applied to the MYONET Steering committee and after approval should be followed by signing of a Data Use Agreement which allows use of data from an individual centre for specific projects.

Myositis International Health and Research Collaborative Alliance (MIHRA)

The Myositis International Health and Research Collaborative Alliance (MIHRA) Foundation is a 501c3 non-profit organisation dedicated to sustainable, highly collaborative research in IIMs, with a clear and dedicated focus on clinical trial readiness (CTR). Emerging from IMACS, MIHRA was founded with a strategic objective to address critical barriers to sustainable research growth in IIMs, while safeguarding the intellectual contributions and authentic voice of the research community (8). MIHRA re-invests all funds back into the IIM research ecosystem, supporting investigator success, education, and clinical excellence. It does so by uniting expertise through strategic platforms that foster multi-stakeholder partnerships to ensure the community's efforts are impactful and inclusive. Significant and remarkable milestone achievements have established MIHRA's altruistic dedication as a catalyst and nurturer to the current and future IIM research community.

MIHRA is honoured to partner with the U.S. Food and Drug Administration (FDA) through its Centre for Drug Evaluation and Research (CDER) in a public-private partnership (PPP) for CTR in IIMs. This collaboration exemplifies MIHRA's global, cooperative approach and continues MIHRA's CTR 2-year journey to delineate trial design elements including trial structures, flare, remission, response, eligibility and analytics. By working closely with patient experts, patient and research organisations, advocacy groups, academic centres, industry partners and government agencies, as well as having professional oversight from organisations like the American College of Rheumatology (ACR), MIHRA brings together diverse expertise and perspectives, and fosters a thoughtful, respectful, and pre-competitive environment to address persistent challenges facing CTR in IIMs. One such challenge in CTR is the inconsistent implementation and training of outcome measures in clinical trials. MIHRA under its FDA partnerships is addressing this by contributing a definitive instrument training and certification platform, developed and implemented with full rights for and input from the original creators. The MIHRA-FDA alliance embodies MIHRA's vision *'Creating a world where we cure myositis together',* by advancing research and accelerating discoveries that no single person or group could achieve alone.

From the outset, patients have been embedded in every aspect of establish-

ing and continuing MIHRA's work for the collective community. The MIHRA Patient Advisory and our network of patient organisations ensure that every project is shaped by the lived experience of those with IIM, from research design to dissemination. This structure reflects MIHRA's conviction that patients are not just stakeholders, but equal partners and leaders in advancing the field. On MIHRA's website: www.MIHRAfoundation.org, one can explore patient-initiated and patient-driven scientific endeavours, including advancing outcome measures, trial strategies and therapies that reflect patient priorities.

MIHRA's pivotal investment in people has established MIHRA as a leader in early-career development. MIHRA strengthens the career pipeline through fellowships, training opportunities and fair compensation for research work and supporting attendance to GCOM, igniting mentorship, collaboration, and cutting-edge science. MIHRA's Career Enhancement Program extends this commitment through structured guidance for emerging leaders in skills development and building long-term careers in IIM research and care.

By nourishing a growing framework at every level, MIHRA continues to accelerate therapeutic breakthroughs. MIHRA's advances remain steady, collaborative, and deeply patient-centred, driving both immediate progress and long-term impact. Through MIHRA's commitment to community, MIHRA is '*creating a world where we cure myositis together*'.

Childhood Arthritis and Rheumatology Research Alliance Juvenile Dermatomyositis (CARRA JDM)

The Childhood Arthritis and Rheumatology Research Alliance (CARRA) Juvenile dermatomyositis (JDM) Committee supports multicentre basic, translational and clinical research addressing the needs of patients with juvenile dermatomyositis and other idiopathic inflammatory myopathies. The Committee's flagship resource is the CARRA JDM Registry, a large inception cohort of JDM and juvenile polymyositis (JPM) patients. The current iteration of the CARRA JDM Registry enrolled >100 patients in its first year, with cumulative enrolment of >450 new-onset JDM/JPM patients to date (9). Paired blood biospecimens are also collected at CARRA JDM Registry visits and banked in the CARRA Biorepository to enable translational research (10). The CARRA JDM Committee also develops Consensus Treatment Plans which form the basis for comparative effectiveness research studies using real-world data gathered in the CARRA JDM Registry (11). To date, Consensus Treatment Plans have addressed moderately severe new-onset JDM, skin-predominant JDM and resistant skin disease, and use of biologics in JDM (12). Consensus Treatment Plans also undergo periodic revision to ensure they are kept up to date with evolving literature and clinical practice. These activities build on a >20-year track record of collaborative JDM research, including an earlier 'Legacy' JDM Registry that facilitated multiple publications on the epidemiology and outcomes of JDM patients (13). The CARRA JDM Committee is led by a Chair and Vice Chair who are elected by the broader CARRA membership to serve three-year terms. The CARRA JDM Committee Chair and Vice Chair hold monthly virtual meetings to engage the full Committee membership, including clinicians (*e.g.* paediatric rheumatologists, physical therapists, and others), researchers, and members of patient/family advocacy groups (*e.g.* Cure JM Foundation). Within the Committee, there exist multiple JDM Workgroups which are formed, led, and sustained in bottom-up fashion by JDM Committee members themselves based on their areas of interest and expertise. Since 2020, active CARRA JDM workgroups have included Translational Medicine for Juvenile Myositis, JDM Clinical Therapeutics, and others (*e.g.* Calcinosis, Rehabilitation & Exercise, Telemedicine, Quality of Care, COVID, and Dermatology Workgroups). Research collaborations occur within these workgroups (10) and between JDM Committee and other CARRA Workgroup members (*e.g.* Mental Health Workgroup). CARRA JDM Committee members also actively collaborate with other myositis organisations including the PReS JDM Working Party, IMACS, MIHRA, MCTC and the development of SHARE guidelines. CARRA has also provided consultative support to industry sponsors and stakeholders, including access to expertise within the CARRA JDM Committee to inform clinical trial design. Efforts are currently underway to disseminate training materials to enhance data completeness and quality within the CARRA JDM Registry, with the goal of facilitating more robust academic and industry research partnerships. The CARRA JDM Committee leaders and membership are committed to governance processes administered via iMyoS, in line with CARRA's strong track record of interorganisational, multinational collaboration.

Paediatric Rheumatology European Society (PReS) Juvenile Dermatomyositis (JDM) Working Party (PReS JDM)

The Paediatric Rheumatology European Society (PReS) Juvenile Dermatomyositis (JDM) Working Party brings together clinicians, scientists, and allied health professionals with the shared aim of improving care, education, and research in juvenile IIM (JIM). With 268 members and representation from over 70 countries, the group applies the PReS 3-pillar structure, advancing basic science, clinical care and education, to support multidisciplinary collaboration and knowledge exchange. The core group meets every two months, and three open meetings are held annually for all members, including one at the PReS Congress. Key activities over the past years have included the launch of several educational resources. Building on the success of the first PReS Myositis Course in Lisbon (2023), the second course was held in London (2025), with a continued focus on practical, cross-disciplinary training. Educational webinars in 2023-2025 have addressed topics including the interferon pathway, lung involvement, muscle biopsy, treat-to-target and CAR T-cell therapy. Research and clinical initiatives have expanded significantly. These include a

multi-centre project on rare JDM complications (ILD, calcinosis), a sleep and fatigue study, and collaborative work on disease activity scoring and Treat to Target frameworks. The group is engaged in efforts to develop a paediatric ILD subgroup, and an international study on necrotising myopathy is in development. Collaborative links with CARRA, IMACS, MCTC and MYONET continue to strengthen, including regular joint meetings, survey projects, and joint manuscript submissions (*e.g.* on JAK inhibitor use).

The working party is also actively engaging patients and families, including efforts to develop a dedicated JDM family day and multilingual communication tools for better inclusivity. Parent-reported concerns, such as fatigue, medication side effects and challenges during transition, continue to inform the group's clinical priorities. With a committed leadership team and a growing international network, the PReS JDM Working Party continues to serve as a dynamic forum for advancing care, education, and research in JIM, while fostering global partnerships to improve outcomes for children and young people living with these rare diseases.

Conclusion

The progress achieved by international myositis networks highlights the power of shared governance in a complex field inherently challenged by multidisciplinary efforts. While united in our commitment to improving diagnostic criteria, outcome measures, and therapies, each organisation contributes distinct strengths: iMyoS provides global coordination, IMACS drives outcome development, MCTC advances clinical trial infrastructure, MYONET delivers registry-based research, MIHRA fosters clinical trial readiness and early-career development through public-private and patient partnerships, and CARRA and PReS lead paediatric initiatives. Together, we form a complementary ecosystem that serves as the scaffolding for a unified global effort. This is further illustrated by the fact that members of one organisation often hold roles in other myositis organisations as well. By strengthening collaboration, minimising duplication, and aligning priorities, the myositis community can accelerate discovery and ensure that advances reach patients more efficiently. United in purpose, our initiatives represent not only a framework for governance but also a collective promise to transform myositis care and research worldwide.

Acknowledgements

Some authors are members of the European Reference Network for Rare Neuromuscular Diseases (ERN EURO-NMD) and/or on Rare and Complex Connective Tissue and Musculoskeletal Diseases (ERN ReCONNET).

Our thanks to PAO (Patient Advocacy Organisations) which comprise of representatives of the following organisations who collaborate to provide patient perspectives: AFM Téléthon, CureJM, Czech Myositis Working Group, DGM German Myositis Working Group, Stichting Spierziekte IBM, Liga Portuguesa Contra as Doenças Reumáticas (Portuguese League Against Rheumatic Diseases), Myositis Association Australia, Myositis Canada, Myosites France, Myositis India, Myositis Support and Understanding, Myositis UK, Nori's Fight, Norsk Revmatikerforbund (Norwegian Rheumatism Association), ReumaNet vzw, Riksförening för myositsjukdomar (Swedish Myositis Working Group), Spierziekten Nederland (Dutch Myositis Working Group), and The Myositis Association.

Affiliations

[1]Division of Neuromuscular Medicine, Department of Neurology, Mayo Clinic, Rochester, MN, USA; [2]Environmental Autoimmunity Group, National Institute of Environmental Health Sciences, National Institutes of Health, Bethesda, MD, USA; [3]International Myositis Society, Göttingen, Germany (representing Patient Advocacy Organizations, PAO); [4]Patient Advisory Board, Myositis International Health and Research Alliance, New Orleans, LA, USA; [5]National Institute for Health Research Manchester Biomedical Research Centre, Manchester University NHS Foundation Trust, The University of Manchester, UK; [6]Department of Rheumatology, Salford Royal Hospital, Northern Care Alliance NHS Foundation Trust, Manchester Academic Health Science Centre, Salford, UK; [7]Neuromuscular Division, Neurology Department, The University of Kansas Medical Center, Kansas City, KS, USA; [8]Rheumatology Department, Unidade Local de Saúde da Região de Aveiro, Portugal; [9]Aveiro Rheumatology Research Centre, Egas Moniz Health Alliance, Aveiro, Portugal; [10]Rheumatology Research Unit, Instituto de Medicina Molecular, Faculdade de Medicina, Universidade de Lisboa, Portugal; [11]Division of Rheumatology, Emory University, Atlanta, GA, USA; [12]Centre for Rheumatology, Division of Medicine, University College London Hospital, London, UK; [13]Department of Paediatrics, Division of Paediatric Rheumatology, Duke University School of Medicine, Durham, NC, USA; [14]Rheumatology Unit, Bnai Zion Medical Center, Faculty of Medicine, Technion Israel Institute of Technology, Haifa, Israel; [15]Department of Paediatric Rheumatology, UCSF Medical School, San Francisco, CA, USA; [16]Department of Rheumatology and Clinical Immunology, St. Josef-Stift Sendenhorst, Sendenhorst, Germany; [17]Division of Rheumatology, Department of Medicine, Solna Karolinska Institutet, Stockholm, Sweden; [18]Department of Gastro, Dermatology and Rheumatology, Theme Inflammation and Aging, Karolinska University Hospital, Stockholm, Sweden; [19]Department of Rheumatology & Queen Square Centre for Neuromuscular Diseases, University College London Hospitals NHS Foundation Trust, London, UK; [20]Rheumatology Department, Great Ormond Street Hospital for Children NHS Foundation Trust and Great Ormond Street Institute of Child Health, University College London, UK; [21]UOC Reumatologia e Malattie Autoinfiammatorie, IRCCS Istituto Giannina Gaslini, Genova, Italy; [22]New Orleans Scleroderma and Sarcoidosis Patient Care and Research Center, Louisiana State University and Tulane University Schools of Medicine, New Orleans, LA, USA; [23]Myositis-Gruppe, Deutsche Gesellschaft für Muskelkranke, Freiburg, Germany; International Myositis Society, Göttingen,

Germany (representing Patient Advocacy Organizations, PAO); [24]Institute of Rheumatology and Department of Rheumatology, First Faculty of Medicine, Charles University, Prague, Czech Republic; [25]Department of Neurology, Amsterdam University Medical Center, Amsterdam, Netherlands; [26]Department of Neurology, Neuromuscular Center, University Medical Center Göttingen, Göttingen, Germany; [27]Department of Neurology and Pain Treatment, Immanuel University Hospital Rüdersdorf, Brandenburg Medical School Theodor Fontane, Rüdersdorf, Germany.

Funding

L.G. Rider's research related to IMACS was supported by the Intramural Research Programs of the National Institutes of Health: the National Institute of Environmental Health Sciences (NIEHS; ZIAES101081), and research grants from the NIH Office of Autoimmune Disease Research and NIH Office of Data Science Strategies. The contributions of the NIH author(s) were made as part of their official duties as NIH federal employees, are in compliance with agency policy requirements, and are considered works of the United States Government. However, the findings and conclusions presented in this paper are those of the author(s) and do not necessarily reflect the views of the NIH or the U.S. Department of Health and Human Services.

Competing interests

L.G. Rider has received intramural research support from NIEHS, NIH, NIH Office of Autoimmune Disease Research, and NIH Office of Data Science Strategies. Unpaid medical advisor to Pfizer and Cabaletta Bio.

M.M. Dimachkie has received in the past 24 months consultancy fees, payment or honoraria for lectures, presentations, manuscript writing or educational events, or participated on a Data Safety Monitoring Board or Advisory Board for AAN (American Academy of Neurology), AANEM (American Association of Neuromuscular & Electrodiagnostic Medicine), Abcuro, Inc., Amicus Therapeutics, Annexon Biosciences, ArgenX, Astellas Pharma, Alexion/AstraZeneca, Cabaletta Bio, Candid Therapeutics, Catalyst Pharma, Covance/Labcorp/Fortrea, CSL-Behring, Creyon Bio, Inc., Dianthus Therapeutics, EMD Serono, Horizon/Immunovant, Ig Society, Inc., Janssen Pharmaceuticals, Kriya Therapeutics, Inc., Medlink, Nuvig Therapeutics, Octapharma, Sanofi Genzyme, Shire Takeda, TACT/Treat NMD, UCB Bio-pharma, and Vertex Pharmaceuticals. In the past 24 months, he has received grants for research from Abcuro, Inc., Alexion/AstraZeneca, Alnylam Pharmaceuticals, Amicus Therapeutics, ArgenX, Biosensics, Bristol-Myers Squibb, Cabaletta Bio, Catalyst Pharma, CSL-Behring, EMD Serono, the FDA/OOPD, GlaxoSmithKline, Genentech, Grifols, Horizon/Immnunovant, Mitsubishi Tanabe Pharma, MDA (Muscular Dystrophy Association), NIH (National Institutes of Health), Nkarta, Inc., Novartis, Octapharma, Orphazyme, Priovant Therapeutics, Ra Pharma/UCB Biopharma, Sanofi Genzyme, Sarepta Therapeutics, Shire Takeda, Spark Therapeutics, and The Myositis Association. He has received royalty payments for manuscript writing from Wolters Kluwer Health/UpToDate and from Elsevier and for discovery relating to healthcare from Zevra Therapeutics.

E. Dourado has received grants from the European Alliance of Associations for Rheumatology (EULAR) and Unidade Local de Saúde da Região de Aveiro, EPE (ULS-RA), and consulting/Speaking gees from Angelini, Boehringer Ingelheim, Cabaletta Bio, Medac and Novartis.

P.C. Gandiga has served as an investigator or oversight committee member/safety officer for multiple industry-partnered and NIH-sponsored clinical trials in autoimmune myositis. He has received past honoraria from: Abcuro, Boehringer Ingleheim, Howard Hughes Medical Institutions, Janssen, Kezar Life Sciences, National Institutes of Health. He has no conflicts relevant to this work.

K. Ardalan reports the following potential conflicts: CARRA JDM Committee Vice Chair (paid consultant position); Cabaletta Bio (research support; scientificadvisory committee/paid consulting; travel costs); Cartesian Therapeutics (Safety Monitoring Committee member; consulting with fees paid directly to CARRA not K.A.); SingHealth (honoraria paid to institution not K.A. for grant proposal pre-review program).

P. Korsten has received honoraria or travel support from Abbvie, AlfaSigma, AstraZeneca, Boehringer Ingelheim, GlaxoSmithKline, Novartis, Pfizer and Sanofi, all unrelated to this paper, and research grants from Diamed Medizintechnik GmbH, all unrelated to this paper.

I.E. Lundberg has received consultancies from Pfizer, Novartis, Argenx, AstraZeneca, Chugai Pharmaceuticals; grants from Janssen, and stock shares for Roche and Novartis.

P.M. Machado has received consulting/speaker's fees from AbbVie, BMS, Celgene, Eli Lilly, Galapagos, Greywolf, Janssen, MSD, Novartis, Orphazyme, Pfizer, Roche and UCB.

L.A. Saketkoo has received research and/or consultancy support from Abcuro, Abbvie, Argenx, aTyr, Boehringer Ingelheim, BMS, Cabaletta Bio, EMD Serono, Janssen, Johnson & Johnson, Mallinckrodt, Merck, Novrtis, Pfizer, Priovant.

J. Vencovský has acted as advisory board member of Argenx, Eli Lilly, Pfizer and UCB, and has received consultancies from Cabaletta, Galapagos, Meiji Seika Pharma, Ouro, and speaking fees from Eli Lilly, Pfizer, Sebin, Sobi and UCB.

J. Schmidt has received payments for advisory boards, speaker's honoraria, travel expenses and research projects from Abcuro, Argenx, Biotest, CSL Behring, Johnson & Johnson, Kezar. LFB, Lupin, Takeda and UCB.

References

1. SCHLÜTER S, DE GROOT I, LUBINUS M *et al*.: Working towards a patient-centred Global Myositis Alliance: call for partnership. *Clin Exp Rheumatol* 2023; 41(2): 214-16. https://doi.org/10.55563/clinexprheumatol/u1pdqm
2. SCHMIDT J, KORSTEN P, ZECHEL S *et al*.: Introducing the international Myositis Society (iMyoS): a novel multiprofessional society to foster the care, education, and research on myositis. *Clin Exp Rheumatol* 2022; 40(2): 210-13. https://doi.org/10.55563/clinexprheumatol/1a7tkf
3. GIANNINI M, BHAI S, BOYER O *et al*.: The classification of myositis: setting the

stage for a universal terminology. *Clin Exp Rheumatol* 2025; 43(2): 178-83. https://doi.org/10.55563/clinexprheumatol/s80tkm
4. ISENBERG DA, CHINOY H, DIMACHKIE MM *et al*.: The origins, evolution and future of the International Myositis Assessment and Clinical Studies Group (IMACS). *Clin Exp Rheumatol* 2022; 40(2): 214-18. https://doi.org/10.55563/clinexprheumatol/yg743i
5. OLDROYD AGS, CALLEN JP, CHINOY H *et al*.: International Guideline for Idiopathic Inflammatory Myopathy-Associated Cancer Screening: an International Myositis Assessment and Clinical Studies Group (IMACS) initiative. *Nat Rev Rheumatol* 2023; 19(12): 805-17. https://doi.org/10.1038/s41584-023-01045-w
6. ZHU C, HAN Y, BYUN J *et al*.: Genetic architecture of idiopathic inflammatory myopathies from meta-analyses. *Arthritis Rheumatol* 2025; 77(6): 750-64. https://doi.org/10.1002/art.43088
7. BISHNOI A, TANG IYK, YOSHIDA A *et al*.: The Myositis Clinical Trials Consortium: an international collaborative initiative to promote clinical trials in adult and juvenile myositis. *Clin Exp Rheumatol* 2025; 43(2): 202-10. https://doi.org/10.55563/clinexprheumatol/k7665a
8. SAKETKOO LA, PAIK JJ, ALEXANDERSON H *et al*.: Collaborative research in myositis-related disorders: MIHRA, a global shared community model. *Clin Exp Rheumatol* 2024; 42(2): 207-12. https://doi.org/10.55563/clinexprheumatol/hc1lsf
9. NEELY J, ARDALAN K, HUBER A *et al*.: Baseline characteristics of children with juvenile dermatomyositis enrolled in the first year of the new Childhood Arthritis and Rheumatology Research Alliance registry. *Pediatr Rheumatol Online J* 2022; 20(1): 50. https://doi.org/10.1186/s12969-022-00709-3
10. NEELY J, SABBAGH SE, DVERGSTEN J *et al*.: Discovery of tissue-specific proteomic signatures in juvenile dermatomyositis highlights pathways reflecting persistent disease activity, clinical heterogeneity, and myositis-specific autoantibody subtype. *Ann Rheum Dis* 2025; 84(11): 1836-51. https://doi.org/10.1016/j.ard.2025.07.020
11. LIU K, TOMLINSON G, REED AM *et al*.: Pilot Study of the Juvenile Dermatomyositis Consensus Treatment Plans: a CARRA Registry study. *J Rheumatol* 2021; 48(1): 114-22. https://doi.org/10.3899/jrheum.190494
12. TARVIN SE, SHERMAN MA, KIM H *et al*.: Childhood Arthritis and Rheumatology Research Alliance Biologic Disease-Modifying Antirheumatic Drug Consensus Treatment Plans for Refractory Moderately Severe Juvenile Dermatomyositis. *Arthritis Care Res* (Hoboken) 2024; 76(11): 1532-39. https://doi.org/10.1002/acr.25393
13. NEELY J, SHALEN J, STURROCK H *et al*.: Access to care and diagnostic delays in juvenile dermatomyositis: results from the Childhood Arthritis and Rheumatology Research Alliance Legacy Registry. *ACR Open Rheumatol* 2021; 3(5): 349-54. https://doi.org/10.1002/acr2.11246