

Introducing the international Myositis Society (iMyoS): a novel multiprofessional society to foster the care, education and research on myositis

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Received on October 29, 2021; accepted
on November 18, 2021.

Clin Exp Rheumatol 2022; 40: 210-213.

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EXPERIMENTAL RHEUMATOLOGY 2022.

Key words: myositis, inflammatory
myopathy, inflammatory muscle
disease

Competing interests: P. Korsten has
received honoraria or travel support
from Abbvie, Boehringer Ingelheim, BMS,
Chugai, Gilead, GSK, Janssen-Cilag, Lilly,
Pfizer and Sanofi Aventis, and research
grants from GSK and Medizintechnik
GmbH, all unrelated to this paper.
The other authors have declared
no competing interests.

Introduction

Why do we need a new society in the field of myositis? Myositis, also termed inflammatory myopathy, inflammatory muscle disorder, or idiopathic inflammatory myopathy, is a severe disease that leads to a significant disease burden, reduced life expectancy, and substantially impaired quality of life. Myositis encompasses unique syndromes including dermatomyositis, juvenile dermatomyositis, anti-synthetase syndrome, necrotising myopathy (synonym: immune-mediated necrotising myopathy), polymyositis, inclusion body myositis, overlap myositis, and several other infrequent conditions, such as granulomatous myositis (1). A commonality of the myositis syndromes is twofold: (a) the disease is usually not limited to an inflammation of the skeletal muscle but also affects extra muscular organs, such as the skin, heart, lung, joints, etc., and can be associated with cancer; (b) in many cases the treatment is not sufficient to fully control the inflammation, restore weakness, and prevent organ destruction.

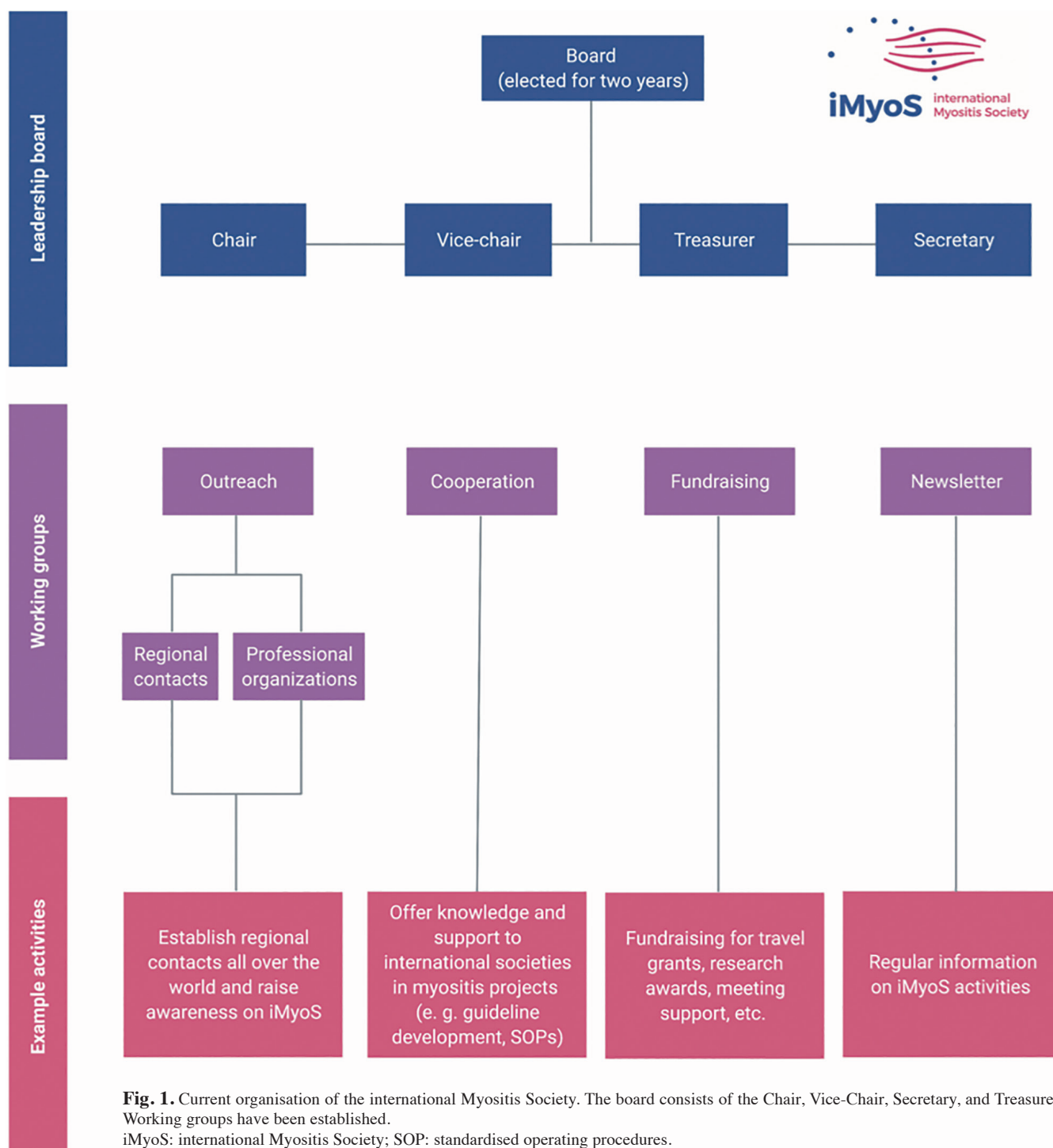
Given the major burden and the complex nature of the disease, there are several imminent shortcomings in the care and research for myositis: patients are often treated by one physician alone, who may or may not be an expert for part of the symptoms, e.g. a dermatologist for the skin symptoms, but who may not be in a position to provide standard care for the involvement of the heart or lung. Thus, optimal care for myositis can only be accomplished by close cooperation between specialties, including rheumatology, paediatrics, neurology, dermatology, pulmonology, cardiology, physical therapy, and many others. Beyond the need for a close collaboration between the required special-

ties, interdisciplinary care is generally hampered by the fact that each professional society usually endorses its own standards of care. Apart from the limitations on care, independently acting professional organisations may not suffice to effectively develop cross-disciplinary treatment modalities and enable multi-disciplinary educational activities.

The vision of the international myositis society (iMyoS) is to overcome the shortcomings above by providing a novel, unique infrastructure that facilitates the collaboration between all medical disciplines required for the optimal care of myositis. Furthermore, iMyoS will foster interdisciplinary educational activities and support research in the field of myositis.

History of the international Myositis Society

The idea for an international Myositis Society was born during the first international conference on myositis in Stockholm in 2015 and further discussed during the second meeting in Potomac 2017, during which the name “Global Conference on Myositis” (GCOM) was coined. The planning of the society was developed during subsequent meetings of international networks on myositis, such as the International Myositis Assessment and Clinical Studies Group (IMACS), Euro-myositis registry (MYONET), and the childhood arthritis and rheumatology research alliance (CARRA) in 2017 and 2018. By a global call through these networks, a voluntary temporary international steering committee was formed consisting of 48 experts from across the globe. This interim steering committee frequently communicated via e-mail, met several times by telephone conferences, and held a face-to-



face meeting during the third GCOM in Berlin, 2019. The committee elected Jens Schmidt as chair and Germany as the fiscal home of the society. The well-established German legal term of an *eingetragener Verein* (e. V.) was chosen as the legal structure of the society. The bylaws were drafted together with the help of national and international lawyers and tax experts; the German

members of the international steering group drafted the bylaws of the society. The proposal was supported by IMACS, CARRA, Euromyositis, MYOSITIS NETZ, European Reference Network on Neuromuscular disorders (ERN EURO-NMD), and the Paediatric Rheumatology European Society (PreS) JDM working group. Once the bylaws were approved by all commit-

tee members and tax and legal experts, the society was officially established on 30 Sept. 2019 in Göttingen, Germany. As the founding board of directors, Jens Schmidt (neurologist, chair), Peter Korsten (rheumatologist, vice-chair), Sabrina Zechel (neuropathologist, secretary), and Silke Schlüter (patient representative, treasurer) were elected. The society was approved by local authorities

and received charity status with exemption from tax. The board established a local virtual office, set up a bank account, and, together with the previous international steering group, decided on iMyoS as the acronym for the society. With the help of some initial donations, the society was able to present an official logo (Fig. 1) and a website (www.imyos.org). Since the finalisation of the website, a steady increase of members from all over the world has been noted, with over 100 members at the time of submission of this editorial. The first general assembly was held in September 2021, during which the founding board members were re-elected. The future goals of the society were discussed, and the first working groups were established (Fig. 1). In particular, further outreach to other networks and professional societies is envisaged.

Goals of the society

The international Myositis Society has developed and formulated several goals for its mid-term and long-term future. These can be divided into the development of diagnosis and treatment standards, collaboration with other major international societies, fostering the education of myositis specialists, promoting and facilitating research on myositis and supporting the bi-annual Global Conference on Myositis (GCOM) meeting. The main goals are summarised in Table I.

Support of the development and harmonisation of diagnostic criteria and standards of care for myositis

The iMyoS aims to build bridges between different international professional societies from Neurology, Rheumatology and Dermatology, among others. The rationale is to join forces and harmonise the standards of care and make the applicable globally. The iMyoS will help to implement those in all existing international and national societies, including the European Alliance of Associations for Rheumatology (EULAR), European Academy for Neurology (EAN), American College of Rheumatology (ACR), American Academy for Neurology (AAN), and many others. These should be available

Table I. Main goals of the international Myositis Society (iMyoS).

- Supporting the development and harmonisation of diagnostic criteria and standards of care;
- Fostering the education of myositis specialists;
- Promoting and facilitating research funding;
- Increasing international awareness;
- Funding and organising the bi-annual Global Conference on Myositis (GCOM) meeting;
- Publishing an annual issue in *Clinical & Experimental Rheumatology* as the society's home journal;
- Offering close collaboration with all existing national and international networks on myositis.

and accessible for a multi-professional team of healthcare professionals that care for myositis patients. As a result, we anticipate a substantial improvement in the quality and availability of the best medical treatment for myositis patients worldwide.

Fostering of the education of myositis specialists and promotion of interdisciplinary curricula and fellowship programmes

The iMyoS aims to develop interdisciplinary educational and exchange training programmes between myositis centres to teach caregivers from all backgrounds and global regions how to manage myositis best. We envisage that this programme will be made available by online webcasts, regional teaching sessions, and educational workshops during GCOM and other meetings relevant to the field of myositis.

Promoting and facilitating the funding for clinical, translational, and basic research on myositis

The iMyoS aims to attract private and corporate donations that will enable the society to meet its goals. Part of the donations will be used to fund research programmes and research awards. Such support can range from small amounts, such as travel grants for junior faculty to present research findings at an international meeting, or larger scale funding that could cover salary and consumables for a dedicated research project. A particular emphasis of the research support will be the multidisciplinary nature of the research project and responsible scientists. It is expected that this measure will significantly move forward research efforts on myositis, especially for young investigators and early career researchers who usually have limited resources.

Increasing international awareness for myositis and providing key contacts for funding bodies and stakeholders

The iMyoS will establish bi-directional cooperation with national and international funding agencies, including the European Union (EU), National Institutes of Health (NIH), European Reference Networks (ERN), European Science Foundation (ESF), Foundation for Research in Rheumatology (FOREUM), among others, to advertise new funding possibilities and to identify suitable grantees of excellence. This effort is expected to catalyse and facilitate funding programmes in the field of myositis.

Funding and organising the bi-annual Global Conference on Myositis (GCOM) meeting

The iMyoS will seek funding to realise the GCOM meeting every two years. Apart from financial support, iMyoS will offer to bring together a team of experts as the scientific committee. iMyoS will foster exchange over the iMyoS website and negotiate contracts with local and global companies that provide their services for the myositis community. We expect that these efforts will greatly help to reduce obstacles during the planning and organisation of the GCOM meeting. It will also help to ensure that the programme remains multidisciplinary and at a high level for the research, education, treatment, and general care for myositis.

Publishing an annual issue on myositis in Clinical and Experimental Rheumatology (CER) as home Journal of the Society will provide a good home for consensus papers, guidelines, and research papers on myositis.

The iMyoS will closely collaborate with CER that envisions publishing the GCOM meeting abstracts and providing a yearly monothematic issue on myositis research and review papers. This collection will be an unprecedented, much-needed addition to the international literature on myositis. It will provide a natural home for cutting-edge science and high-class reviews and standards of care that are endorsed by iMyoS. This interaction with CER will substantially increase the myositis literature's visibility on a global level and can trigger clinical and basic research studies.

Offering close collaboration with all existing national and international networks on myositis

Similar to mutual collaborations with professional societies, iMyoS will cooperate with all existing networks active in myositis, including IMACS, MYONET, The Myositis Association (TMA), MYOSITIS NETZ, CARRA, PreS-JDM, ERN EURO-NMD, ERN ReCONNECT, and many others. Such

cooperation can merely be the share of resources and help to avoid duplications and reduce costs. Importantly, by providing an "umbrella network," iMyoS expects that efforts by the existing networks can be strengthened and that the multidisciplinary and transnational nature of activities can be facilitated and supported. We hope that this measure will significantly improve the multidisciplinary standards of care and will improve individual treatment for all patients with myositis. iMyoS will *not* replace or duplicate any of the existing network activities.

Vision of the society

At the time of writing this editorial, iMyoS is a young and growing society. The foundation of iMyoS and its legal establishment has been a success story that has already attracted many internationally renowned experts in the field. In the next two years, we expect the society to grow further, to become increasingly recognised internationally, and to define its role among all existing networks without duplicating or

replacing currently existing organisations. Furthermore, iMyoS has started its day-to-day work with the organisation of working groups that help realise the society's mid- and long-term goals. Finally, iMyoS invites anybody interested in the field of myositis to become an active member and help shape its future. iMyoS will hold at least two general assemblies per year, coming up next in Spring 2022.

Acknowledgments

J. Schmidt, P. Korsten and S. Zechel are members of the European Reference Network for Rare Neuromuscular Diseases (ERN EURO-NMD).

We thank L. Rider, I. Lundberg, and F. Miller for their invaluable support during the foundation of iMyoS.

We are grateful to Carole Stein (Florida, USA) for a donation that facilitated the development of the iMyoS website.

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