



New international myositis society (iMyoS): guidance and support for diagnosis, interdisciplinary care and research in myositis

On behalf of all iMyoS members: Jens Schmidt^{1,2}, Peter Korsten³, Sabrina Zechel⁴, Silke Schlüter⁵

- 1) Dept. of Neurology, University Medical Center Göttingen, Germany
- 2) Dept. of Neurology and Pain Therapy, University Hospital of the Brandenburg Medical School
- 3) Dept. of Nephrology and Rheumatology, University Medical Center Göttingen, Germany
- 4) Institute of Neuropathology, University Medical Center Göttingen, Germany
- 5) German myositis patient support group, German Society for Myopathies, Freiburg, Germany

Background

Myositis is a neuromuscular disorder that can affect the skeletal muscle, skin, lung, heart, and other organs. Its pathogenesis is complex, and the diagnosis requires careful workup of muscle inflammation, organ involvement, and auto-antibody testing. Treatment strategies need to consider the individual disease course and extramuscular organ involvement.

The nature of the disease requires a dedicated interdisciplinary work-up and care involving pediatricians, rheumatologists, dermatologists, neurologists, pulmonologists, cardiologists, pathologists and rehabilitation specialists.

Diagnostic delay or insufficient treatment often cause severe burden of disease. Main shortcomings relate to different approaches for diagnosis and treatment that vary between specialties or geographic regions.

The newly established international myositis society (iMyoS) aims to overcome these shortcomings.

Methods

Over the course of three years, major international networks have been contacted, including IMACS, ERN EURO-NMD, ERN ReCONNECT, MYOSITIS NETZ, Euromyositis, CARRA, and PRES JDM. All networks agreed on the need for an international myositis society and supported its foundation. A temporary international steering committee was established by a

non-exclusive call through the aforementioned networks. A local steering committee drafted bylaws and organized the legal and administrative foundation of the society.

Results

The steering committee selected Germany as home of the society. Members from Germany formed a local steering committee that drafted bylaws in German and English. The bylaws were approved by experienced lawyers and formally accepted by the international steering committee.

The main aims of the international myositis society are to 1) Support the development and harmonization of diagnostic criteria and guidelines of care of myositis and help to implement those in all other international and national societies (e.g. AAN, EULAR, ACR, EAN); 2) Foster the education of myositis specialists and promote interdisciplinary curricula and fellowship programs; 3) Increase international awareness of myositis, promote funding and provide key contacts for funding bodies and other stake holders including NIH, EU, ERN, ESF, FOREUM and others, and liaise with a Journal as home for the society; 4) Provide support for the local organizing committee of the global conference on myositis (GCOM) every two years.

The local steering committee met in person to establish the international myositis society e.V. in Goettingen, Germany. The bylaws were officially approved by German court and charity status as well as tax-exempt status was formally granted by financial authorities. The website development has been facilitated by initial charity donations and has been finalized recently. The website development is expected to be finalized soon. An international, open call for membership will follow. Clinical Experimental Rheumatology has agreed to serve as home Journal of the Society and to host a yearly supplement on myositis and to cover the proceedings of the biannual conference on myositis (GCOM). The society will meet in person during the next GCOM in Prague in 2022 and elect a president and board members. Work of the society will be divided into sub-committees that focus on certain tasks such as imaging, diagnostics, treatment etc.

Conclusion

Foundation of the international myositis society iMyoS is a major achievement in the field of myositis. It is expected that the society will help to improve future diagnosis and treatment of myositis by implementing interdisciplinary standards of care on a global scale. All standards will be developed in close collaboration with all respective professional societies, including patient representatives and allied health professionals.