Editorial

Working towards a patient-centred Global Myositis Alliance: call for partnership

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Myositis is a rare autoimmune group of conditions, characterised by chronic muscle inflammation, which are difficult to diagnose and treat. Myositis patients show muscle weakness, often affecting other organs like the skin and lungs, leading to significant impairment and reduced quality of life, including pain (1) and fatigue (2), frequent flares, and hospitalisations. Patients and their care partners often feel isolated, vulnerable, even helpless, and anxious about their future. Between countries, wide differences exist in accessing proper diagnosis, treatments, and quality of care (QoC), including access to support groups. These differences lead to inequality, insufficient care, and support, which becomes another stress source for patients.

Patient support groups are a key pillar for patients, care partners and their families dealing with myositis on a daily basis, at the same time these support groups play an important role in bringing the voice of the patient to other stakeholders. Many developed countries do have support groups and their number is growing. Despite their differences, they share similar ambitions, goals, and challenges. We believe that we need to strive for a stronger partnership in the years to come to benefit the myositis patients we represent and foster patient organisations elsewhere.

Myositis patient associations activities

Most countries had initially loose support groups that have now become active patient organisations, avid to engage with other peers. Their mission is focused on improving the lives of patients and care partners affected by myositis through patient support and education, including advocacy, awareness and research in the form of grants or patient-centred initiatives. Several varied activities are carried out in each country; some have the resources needed for organising patient conferences, while others might concentrate on creating informational brochures and educational videos and podcasts, virtual or in-person support meetings, or offer 24/7 support groups on platforms such as Facebook or Clubhouse. During the pandemic, the number of virtual meetings increased and created new opportunities to connect. Although some patient support organisations do fundraise for academic research, this is not necessarily possible or allowed in all countries due to existing laws.

Increasing collaborations in myositis

Patient organisations play an important role in bringing the voice of the patient to other stakeholders in the Myositis community. Often, group members are involved in collaborations with both medical providers and the myositis research community, *e.g.* the International Myositis Assessment and Clinical Studies Group (IMACS) has many patients among their specific interest groups, also the Outcome Measures in Rheumatology (OMERACT) and the recently founded International Myositis Society (iMyoS) (3) have allocations for patients to play a role as subject matter experts. Patients can act as Patient Research Partners, co-authors in scientific papers, and patient representatives in meetings, workshops, guideline development, etc. Patient organisations can also present their own findings based on peer-review data in collaboration with academic partners or provide patient feedback on the myositis journey in front of government

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agencies. These are important opportunities to represent and highlight the patient perspective, which in turn will improve the results of research and guarantee their dissemination to the patient community. Given this evolution, patient organisations may be more likely to team up with their colleagues across borders to learn from one another, as well as to reach out to more patients and stakeholders to have an even bigger impact. A recent example was the joint initiative of leaders from the Czech, German, Swedish, and Dutch patient organisations to develop patient sessions during the biannual Global Conference on Myositis (GCOM) meeting in Prague. These sessions were well received by patients, researchers, and healthcare providers, who called for extension and implementation in future conferences.

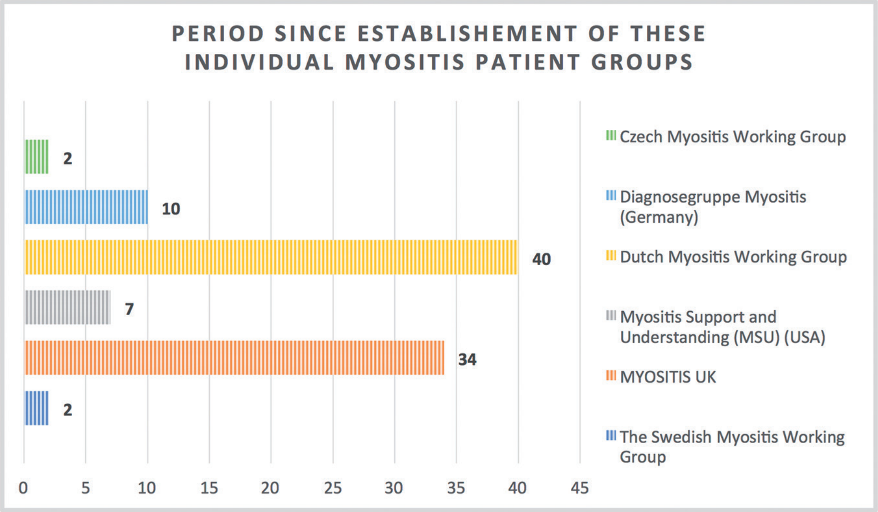

Fig. 1. This graphic gives some examples of how many years the individual myositis groups have been active in supporting myositis patients and their families.

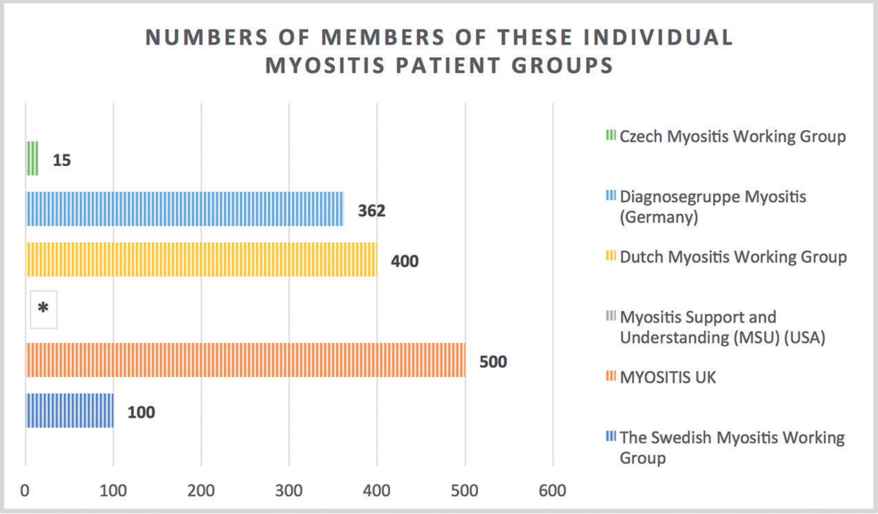

Fig. 2. Current status (October 2022) of the members of the myositis patient groups from Figure 1. *MSU has an optional membership policy. The support groups online have a combined reach of about 8-10 thousand patients, including all patient subcategories.

Goals, challenges, and opportunities

Such partnerships offer both opportunities and challenges for all parties involved. Probably the biggest challenge is to find common ground among the organisations' busy schedules and ongoing programmes, given that each organisation has a varied framework, and different priorities, and represents diverse stakeholders (Fig. 1, 2). However, this can be done by focusing on the common goal that we all share, namely improving the lives of the people living with myositis and having an open channel of communication within countries. Another important challenge is to proportionally allocate myositis research funding to different research areas. In general, most funding is spent on clinical and basic research, which is very important, but also very time and money-consuming.

Patients however increasingly mention another important unmet need, namely studies that focus on the quality of life in the "here and now". Important and much-requested topics are exercise and rehabilitation, which are now considered important therapies by themselves, as well as psychosocial support for patients and their caregivers.

Given our common goal, the call for a global myositis patient alliance gets magnified. Establishing such a partnership is an immense challenge, but also a dream shared by many. It offers opportunities to empower our patient community and advocate for patients across the globe, while improving access to clinical trials for all patient subtypes, and a better standard of care and support. Adopting best practices by benchmarking suitable support strategies from our partners can result in the more appropriate use of our resources including sharing relevant patient data on the burden of disease that impacts patient QoL. Increasing our partnerships with international research teams in projects directly relevant to our diverse patient populations benefits many of the rare patient subtypes that are often ignored in research due to their low numbers.

Additional opportunities for engagement do exist. The biannual GCOM is a great place to work together in the content planning of future meetings, *e.g.* having more patient sessions (including research training), more patient driven research, and consequently more engaged patients attending from all over the world. Patient participation should not be considered an afterthought, rather should be a fundamental part of a myositis conference, where trained patients bring to the table the perspective of their peers and freely interact ideas with researchers in different clinical fields. In addition, Sites such as iMyoS offer the patient community a one-stop platform by listing information and contact details of all patient organisations on their website. Hopefully, this is the beginning of long-term endeavours such as a global registry, including antibody subgroups, increasing international patient involvement in future research, and in other upcoming conference programmes.

Finally, a big opportunity for a patient-centred Global Myositis Alliance would be the establishment of World Myositis Day. Currently, patient groups from several countries, including a loose coalition with members of North America and Australia, are discussing this much-desired concept. This day would bring attention and myositis awareness across the globe. Taking all goals, ambitions, and challenges into consideration, joining forces and closing ranks is the only way forward if we want to improve the lives of people with myositis.

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