



GCOM 2024

5th Global Conference
on Myositis

March 13-16, 2024
Pittsburgh, PA - United States

Patient Session

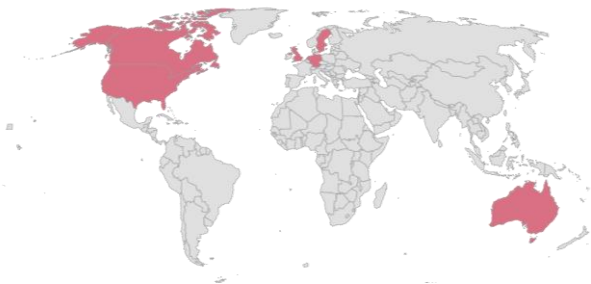
Friday, 15 March 2024



WORLD MYOSITIS DAY

History of the World Myositis Day - WMD

- Prof. Dr. Jens Schmidt initiated the editorial at for the international myositis patient representatives
- Outlines among other things to raise awareness of myositis.
 - Silke Schlüter suggested the implementation of a World Myositis Day.
- Other international patient representatives eager to forward on this.



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Editorial

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

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Key words: myositis, patient advocacy, patient organisation

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

ness 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

History of the World Myositis Day - WMD



Which date?

As National Myositis Awareness Day is celebrated in the USA on September 21, every myositis patient representative agreed on this date for the WMD.

Who to contact for recognition through the WHO?

- Silke contacted: The UN, the WHO & the German Minister of Health regularly & repeatedly for over a year
- No feedback: So, all patient representatives decided to celebrate the WMD on September 21 anyway and to forego recognition by the WHO for the time being.

(Official recognition by the WHO is still being pursued.)

History of the World Myositis Day - WMD

A logo was needed now. What kind of logo should it be?

- Collecting ideas and suggestions
- Forwarding through Ingrid de Groot and Christine Lowe to two graphic designers
- Voting on the drafts.
- Marc Bobolakis of Larkscapes Design (Australia) created the final logo.



Final Logo of the World Myositis Day - WMD



**World
Myositis
Day** 21 Sept

Announcement of the World Myositis Day 2023



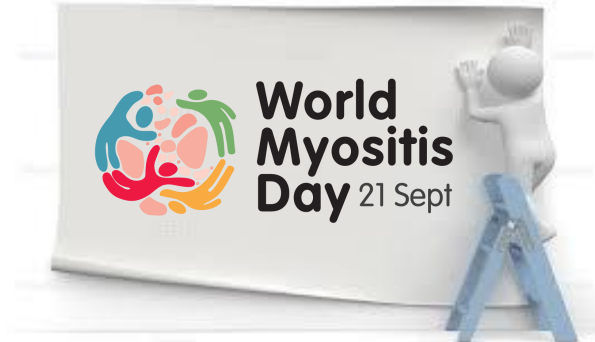
Dissemination via:

- Webpages of the myositis patient groups
- iMyoS Webpage
- Instagram, Facebook, X, LinkedIn
- Newsletters
- Radio (Australia)

Activities on the World Myositis Day - WMD

WE are considering for the future:

- Special myositis webinars
- Charity Runs
- Interviews (Radio/TV)
- Special Myositis Podcasts
- Poster advertising
- TV/Radio advertising
- ...
- ...



Activities on the World Myositis Day - WMD

What would YOU do?

Help us to raise awareness of myositis worldwide. How can we increase impact for WMD?

- 1.....
- 2.....
- 3.....
- 4.....
- 5.....



Thank you for your attention & support!



**World
Myositis
Day** 21 Sept