

GERMAN PATIENT SUPPORT GROUP FOR MYOSITIS

Diagnosegruppe MYOSITIS

The Diagnosegruppe Myositis was established in 2012 as “Aktion Myositis” by Prof. Dr. Jens Schmidt, Dr. Martin Taylor, and Sigrun Matthiesen, and joined 2014 the German Society for Neuromuscular Diseases (Deutsche Gesellschaft für Muskelkranke – DGM). The DGM has over 9300 members. 351 members are registered with myositis. The activities of the group are planned and implemented by nine myositis-patients, two relatives and one myositis specialist as medical advisor. A close cooperation exists with the German myositis network MYOSITIS NETZ.

Our mission

As German patient support group, we represent the interests of those affected and their relatives. We want to:

- promote and support research projects
- establish a network of patients, relatives, physicians, scientists, and other caregivers
- educate patients, physicians, and other care givers
- help establish diagnostic criteria
- improve access to information for patients and relatives
- strengthen the exchange between those affected
- help for those in fear of the disease burden
- inform and educate the public about this disease and its burden
- establish and support patient registries

Our activities with national and international myositis groups/ organizations

- participate in national and international myositis meetings
- Networking & collaboration with national and international myositis networks, myositis supportgroups and myositis patient groups
- Associated with MYOSITIS NETZ, iMyoS, TMA
- Contribution to the international project: Consensus Evidence-based Guidelines on Exercise and Rehabilitation, the International Myositis Assessment and Clinical Studies (IMACS) Group, in particular the IMACS Rehabilitation & Exercise Special Interest Group.



MYOSITIS NETZ-Meeting



GCOM 2019



GCOM 2019

Our daily activities

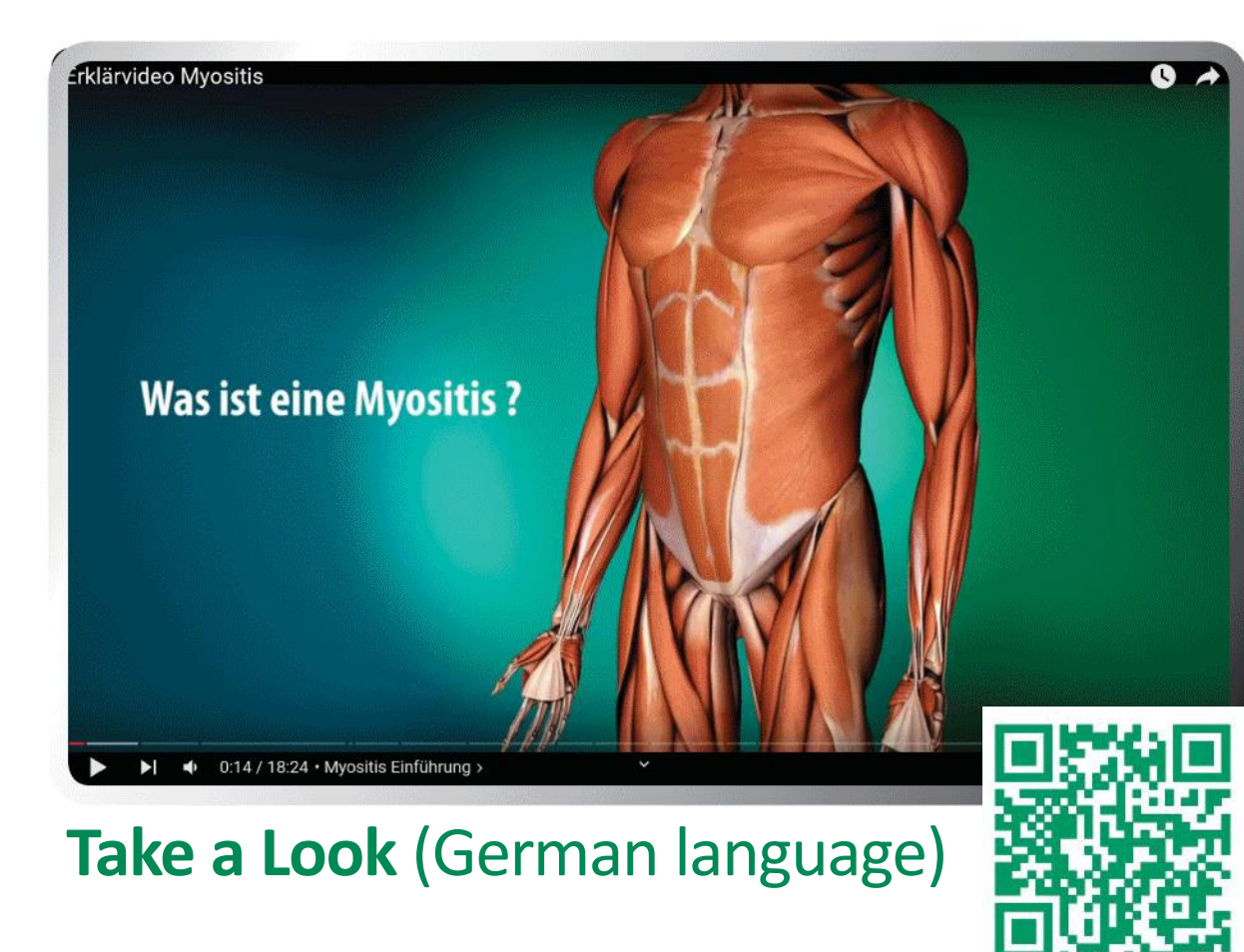
An important goal is to support patients with myositis and their relatives. We provide support over the phone or email. We offer a monthly online discussion group for myositis patients to connect with each other. An online myositis discussion group for relatives is scheduled every two months. We provide information about our activities via Facebook group, Facebook page, Instagram and via the DGM and MYOSITIS NETZ websites. We regularly send out our myositis newsletter and publish myositis news in the “Muskelreport” (newspaper of the DGM).

Our special projects

- Organize symposia & “information days” with topics for one specific disease
- Support research projects
- Funding the Myositis Trainee Award “Myositis Nachwuchs Forschungspreis”
- Meetings with experts from various clinics
- Conduct a myositis charity run
- Design and distribution of an explanatory video on myositis
- Design and dissemination of myositis podcasts on topics related to myositis
- Information brochures



Working Group “Diagnosegruppe Myositis”



Take a Look (German language)



Listen to it
(German language)

Conclusions

Myositis is a rare disease and diagnosis is often difficult and lengthy. We are committed to provide the best possible support to affected individuals and their families on the road to a diagnosis and in living with myositis, because our slogan is: “MYOSITIS – Ohne Muskeln GEHT es nicht!” (MYOSITIS – Nothing GOES without muscles!)

