



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

ICNMD meeting (online) 21-22 & 28-29 May 2021

On behalf of all iMyoS members: Jens Schmidt<sup>1,2</sup>, Peter Korsten<sup>3</sup>, Sabrina Zechel<sup>4</sup>, Silke Schlüter<sup>5</sup>

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## Goals of the international myositis society

- Support the development and harmonization of diagnostic criteria & guidelines of care of myositis and help to implement those in all other international & national societies (AAN, EULAR, ACR, EAN...)
- Foster the education of myositis specialists and promote interdisciplinary curricula and fellowship programs
- Increase international awareness of myositis, promote funding and provide key contacts for funding bodies and other stake holders including NIH, EU, ERN, ESF, FOREUM etc.
- Provide support for the local organizing committee of the international myositis meeting every two years



## What the society will NOT do

- The society will **NOT** exclude or replace any speciality or existing group
- It will **NOT** replace networks like IMACS, MYONET, CARRA etc., but provide a supportive infrastructure and platform to exchange knowledge between groups, avoid duplicate efforts etc.



## Formal or informal support from existing groups/ networks:



IMACS

ERN EURO-NMD

ERN ReCONNET

MYOSITIS-NETZ

Euromyositis

CARRA

PRES JDM

and others



## Foundation of the Society



- With help from IMACS and Euromyositis, an international advisory panel was set up
- Germany was elected as the home of the society
- A local steering group was asked to establish the Society:  
  
Silke Schlüter, Peter Korsten, Jana Zschüntzsch, Tobias Ruck, Cord Sunderkötter, Ingo Tarner, Ulf Müller-Ladner, Jens Schmidt
- The local steering group drafted bylaws
- Help was received by local lawyer and international tax attorney
- Draft bylaws were discussed during first face-to-face meeting of the temporary steering committee at GCOM 2019



# The final statutes (title page)



Satzung / Statutes "International Myositis Society e.V. "

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## **Satzung des eingetragenen Vereins „International Myositis Society e.V.“**

## **Statutes of the registered association „ International Myositis Society e.V. “**

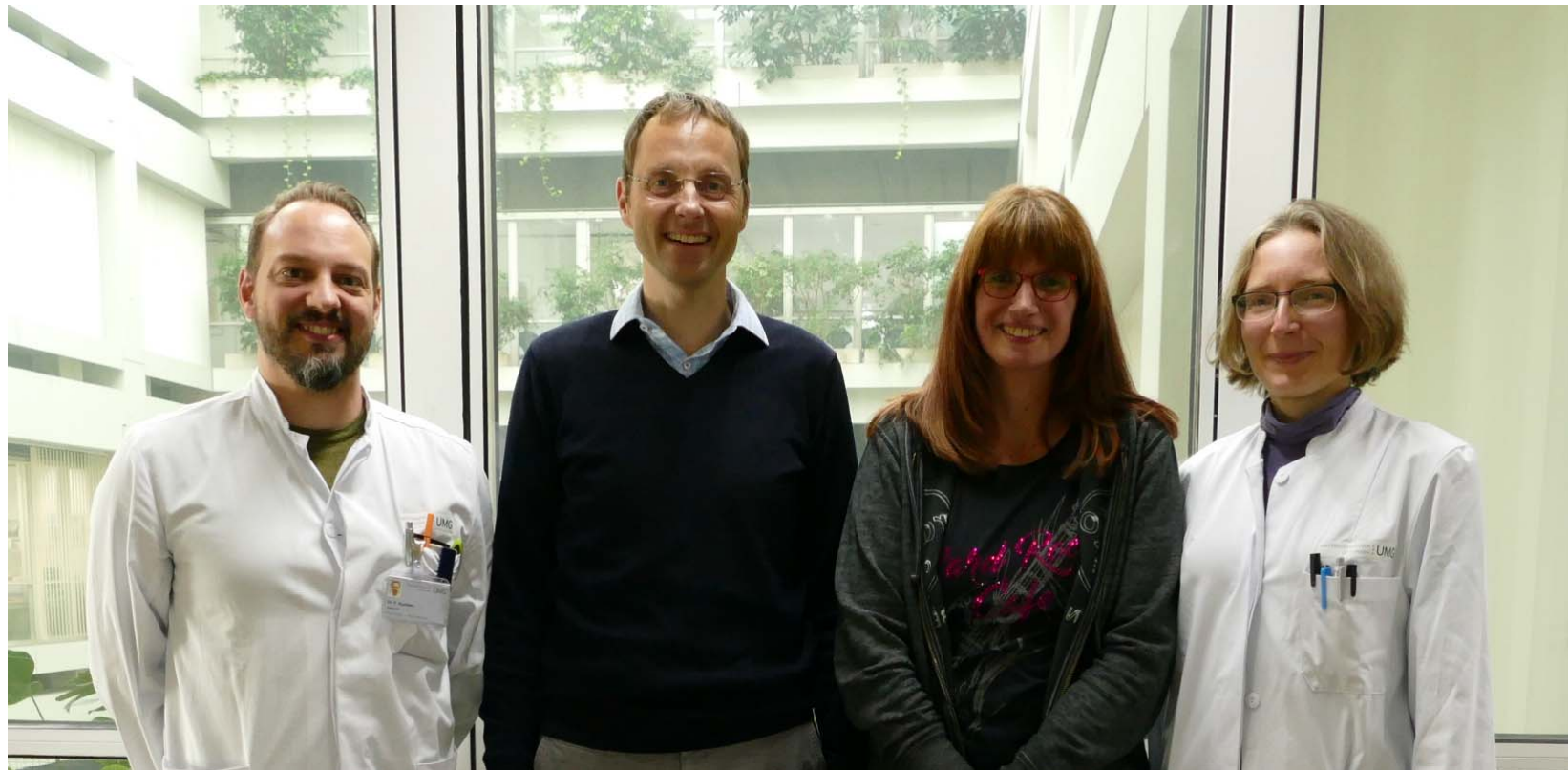
<b>§ 1 Name, Sitz, Geschäftsjahr</b>	<b>§ 1 Name, registered office, financial year</b>
<p>Der Verein führt den Namen " International Myositis Society e.V."</p>	<p>The association bears the name " International Myositis Society e.V."</p>
<p>Er soll in das Vereinsregister eingetragen werden und führt dann den Zusatz "e. V."</p>	<p>It shall be entered in the register of associations and shall then bear the addition "e. V."</p>
<p>Der Verein hat seinen Sitz in Göttingen.</p>	<p>The association has its registered office in Göttingen.</p>
<p>Das Geschäftsjahr des Vereins ist das Kalenderjahr.</p>	<p>The financial year of the association is the calendar year.</p>
<p>Der Verein verfolgt ausschließlich und unmittelbar gemeinnützige und mildtätige Zwecke im Sinne des Abschnitts "Steuerbegünstigte Zwecke" der Abgabenordnung.</p>	<p>The association pursues exclusively and directly non-profit and charitable purposes within the meaning of the section "tax-privileged purposes" of the German Tax Code [AO].</p>



## Inaugural meeting of the Society



Election of the board of iMyoS (from left to right): Peter KORSTEN (vice chair, Rheumatologist), Jens SCHMIDT (chair, Neurologist), Silke SCHLÜTER (Treasurer, Patient representative), Sabrina ZECHEL (Secretary, Neuropathologist)





## Foundation of the Society



- The minutes of the inaugural meeting together with a signed hardcopy version of the bylaws were submitted to court by the local attorney
- Draft bylaws have been formally approved by local court
- Based on evaluation of statutes and minutes of inaugural meeting, financial authorities have granted charity status and tax exemption
- Membership fee: 50 EUR has been set as yearly fee





## Recent achievements |



- With help from an international advisory panel, **iMyoS** was elected as acronym
- Bank account: successfully set up at *Deutsche Bank*
- Website design and logo design were facilitated by initial charity donations
- Logo design has been finalized in April 2021





## Recent achievements II

- Finalization of website design will be achieved in May 2021
- Website launch is expected in the coming days!

Please check: [www.imyos.org](http://www.imyos.org)

- Clinical Experimental Rheumatology (<https://www.clinexprheumatol.org/>) has agreed to serve as the home Journal of the Society and to host a yearly supplement on Myositis and cover the proceedings of the biannual conference on myositis (GCOM)



## Recent achievements III

- An international call for membership will be circulated soon via all existing networks
- Together with all new members of the society, a broad outreach to all clinicians, care-givers, patients, scientists and stake-holders will follow
- Face-to-face meeting of the Society and elections are planned for the **2022 myositis meeting in Prague** (hopefully)



**Thank you for your support!**

**Questions or suggestions?**

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