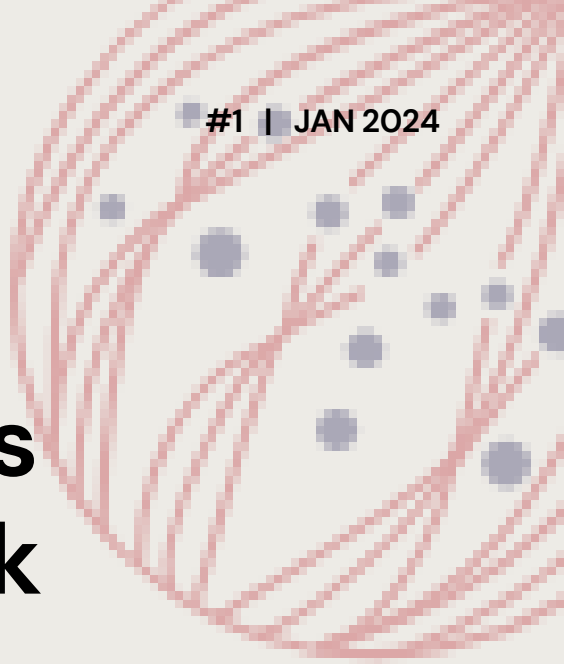


Global Myositis Network



Interdisciplinary Research Project on Inflammatory
Myopathies, Myositis

INTRODUCTION

Dear all,

Dear all, welcome to the 1st issue of the MYONET annual newsletter. The aim of this publication is to provide members with updates regarding the MYONET collaboration and the associated registry. We would welcome your feedback on items featured in the newsletter or suggestions for the future development of the collaboration / registry. This issue will provide:

- An overview of the MYONET collaboration / registry.
- An introduction to the MYONET Steering Committee members.
- The number of contributing centres and their geographical distribution.
- The overall registry data collected since 2010.
- The overall registry output since 2010.
- The top recruiting centres in 2023.
- A request for centres to recruit more JDM cases.
- Details of the newly proposed Data Sharing Agreement.

MYONET

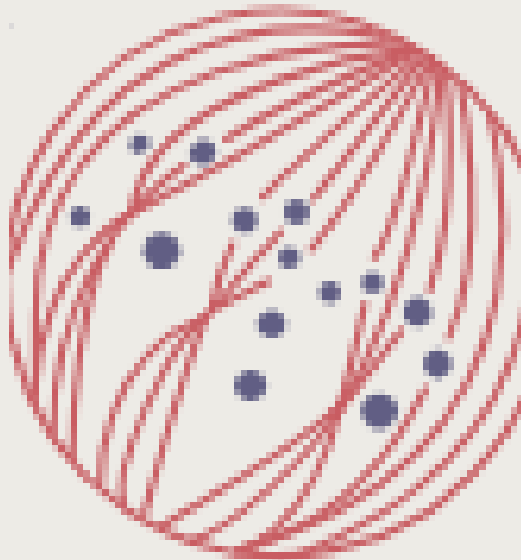
OVERVIEW OF THE MYONET COLLABORATION / REGISTRY:

MYONET is an international collaboration between clinicians and researchers interested in furthering our understanding of the inflammatory myopathies and related conditions. It takes an interdisciplinary approach, including representation from neurologists, rheumatologists, dermatologists, neuropathologists, and basic scientists with expertise in genetics, proteomics, and immunology. Established in 2010, MYONET (formerly EuMyoNet) developed the largest inflammatory myopathy disease registry in the world. Originally referred to as the EuroMyositis Registry, it has since been renamed the MYONET registry, to reflect the now global nature of the collaboration / registry.

The registry allows for the collection of uniform, longitudinal data from patients with inflammatory myopathies, to further our understanding of disease course and progression. Data collected and recorded within the registry includes the name of the base hospital and doctor, the patient's ethnicity, month and year of birth, date of disease onset, diagnosis, clinical features, laboratory investigations, past and current medications,

auto-antibody status, and muscle biopsy details. Longitudinal data is also available for patients, including manual muscle testing, activity assessment, damage index, health assessment questionnaires, functionality index and quality of life index.

Doctors from around the world are invited to join the collaboration and to record patient's clinical details into the registry. The data can then be used either by the doctors at each base hospital, for clinical or research purposes, or by MYONET collaborators wishing to access registry data (with the permission of the MYONET Steering Committee) for research purposes.



INTRODUCTION TO THE MYONET STEERING COMMITTEE MEMBERS:

The steering committee comprises of 3 founder members and 8 representative members.

The **founder members**, listed below, include three consultant rheumatologists:



01. Prof. Hector Chinoy
University of Manchester |
Manchester | UK



02. Prof. Ingrid Lundberg
Karolinska University |
Stockholm | Sweden



03. Prof. Jiri Vencovsky
Charles University | Prague |
Czech Republic

The **representative members**, listed below, include:



Prof Jens Schmidt
University Hospital Berlin
| Germany | **Neurology**
Representative



Prof Lucy Wedderburn
University College London
| UK | **Paediatric**
Representative



Dr Liza McCann
Alder Hey Childrens
Hospital | UK |
Paediatric
Representative



Prof Gouchan Wang
University Hospital |
Beijing, China | **Global**
Representative



Associate Prof
Louise Diederichsen
Copenhagen University
Hospital | Copenhagen
Denmark | **International**
Representative



Dr James Lilleker
University of Manchester
| Manchester, UK | **Social**
Media Representative



Prof Olivier
Benveniste
University of Paris |
France |
International
Representative

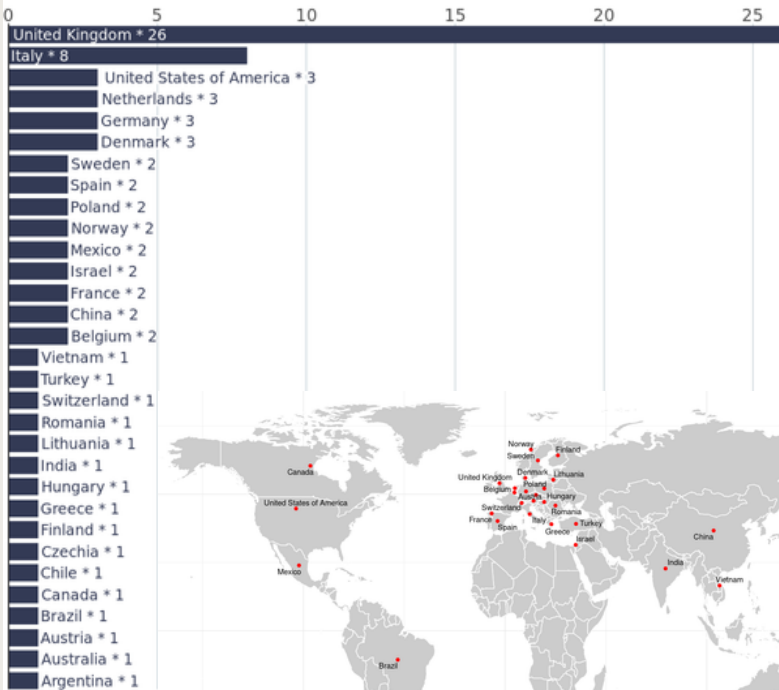


Niels Steen Krogh
Managing Director of
Zitelab ApS |
Denmark | **Technical**
Lead

NUMBER OF CONTRIBUTING CENTRES AND THEIR GEOGRAPHICAL DISTRIBUTION:

Since 2010, **80** centres have joined the **MYONET** collaboration and contributed data to the registry. These centres are spread over **31** countries.

Number of contributing centres per country



The collaboration is open to new centres who wish to join and details on how to apply can be obtained from our website (details to follow).

OVERALL REGISTRY DATA COLLECTED SINCE 2010:

Since 2010 the registry has collected both cross sectional and longitudinal data from patients with inflammatory myopathies, latest figures shown below:

No. Patients recruited	6705
Patients => 2 study visits	2213
Total study visits	13105
Patients recruited with JDM	201

OVERALL REGISTRY OUTPUT SINCE 2010:

Since 2010 there have been various projects completed using registry data, resulting in a number of publications that can be viewed on our website <https://www.myonet.info/>

Details of how potential collaborators can access registry data for use in their own projects can also be found on our website.

LIST OF PROJECTS USING REGISTRY DATA:

2021

Clinical manifestations of extra muscular disease in dermatomyositis and anti-synthetase syndrome. Results from the EuroMyositis registry (Ryan Hum, James Lilleker, The University of Manchester, UK)

Survival prediction in myositis associated interstitial lung disease using the interstitial lung disease – GAP model (Cecilia Pisoni, María Laura de la Torre, Medica e Investigaciones Clinicas, Argentina)

2020

2019

Cardiovascular consequences of systemic inflammation in IIM (Louise Diederichsen – Copenhagen University Hospital – Denmark)

Biomarkers as predictors to treatment response and outcome (Fabricio Espinosa-Ortega, Helena Alexanderson, Maria Holmqvist, Ingrid Lundberg, Karolinska Institutet, Stockholm, Sweden)

2018

2015



The Euromyositis Registry: Myositis Serology (Zoe Betteridge, Neil McHugh, University of Bath, UK)

The Euromyositis Registry: A Multinational Collaborative Approach to Rare Disease Research (James Lilleker, Janine Lamb, Hector Chinoy, The University of Manchester, UK)

Prediction of disease progression in patients with polymyositis and dermatomyositis using the Euromyositis registry (Katharina Zachariassen, Britta Maurer, Ingrid Lundberg, Karolinska Institutet, Stockholm, Sweden)

2014



Long term outcomes in childhood myositis (Christina Boros, Lucy Wedderburn, UCL, London)

TOP RECRUITING CENTRES IN 2023:



A REQUEST FOR CENTRES TO RECRUIT MORE JDM CASES:

The registry currently has around **201** recruited cases of **JDM** and with help from participating centres, we would like to increase this number. If there are any clinicians who treat juvenile cases and would like to become involved, please contact Mr. Paul New or Dr James Lilleker using the contact details below.

DETAILS OF THE NEWLY PROPOSED DATA SHARING AGREEMENT:

Finally, MYONET is updating both its Data Sharing Agreement (DSA) and its Data User Agreement (DUA) for the registry.

The DSA will be signed by all new members wishing to join the registry as well as all existing members who are currently entering registry data. The DSA will be finalised in the New Year when we will be contacting centres to arrange for signatures. We will appreciate the assistance of participating centres when undertaking this task


The DUA will be signed by all new collaborator wishing to access registry data for use in their own research projects (once approved by the steering committee).

CONTACT DETAILS:

If you wish to contact a member of the MYONET team regarding the collaboration, the registry, or the newsletter, please do so using the contact details below.


Mr. Paul New

MYONET Administrative Support

 paul.new2@nca.nhs.uk

Dr James Lilleker

Social Media Representative

 james.lilleker@manchester.ac.uk

