

## Biennial report

### Study Groups

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#### **Title of the study group:** EULAR Study Group on Myositis **MyoNet**

Study Group Leader's name: Ingrid Lundberg (Karolinska Institutet and Karolinska University Hospital)

Date of annual report submission: 2020-03-26

#### **Summary of last year's activities**

##### **EULAR 2018 in Amsterdam**

Thursday June 14, from 8.00- 9.45

The meeting provided an update on the Euromyositis register, the most important tool and activity of the MyoNet study group. We also had an introductory report on the recently approved FOREUM project. 18 participants were present.

- Welcome and introduction of participants – Ingrid Lundberg
- Aims of Study group MyoNet – Ingrid Lundberg
- Euromyositis – update: New classification criteria module; tool to extract data – Jiri Vencovsky
- Update from FOREUM approved The IMPROVEMENT project – Hector Chinoy and Lorenzo Cavagna
- Case discussions -
- Juvenile dermatomyositis-Lucy Wedderburn
- EULAR/ACR classification criteria for myositis- next step – Ingrid Lundberg
- Presentation of new projects - all
- Discussions –all

##### **EULAR 2019 in Madrid**

Thursday June 13 from 8.15- 9.45

The meeting provided an update on the Euromyositis register. We had a report on the FOREUM project and a report from the pediatric community in relation to Juvenile dermatomyositis. One new project that has been approved by the Euromyositis steering committee on prognosis for damage in myositis was presented. 22 participants were present.

- Welcome and introduction of participants – Ingrid Lundberg
- Aims of Study group MyoNet – Ingrid Lundberg
- Euromyositis – update (classification criteria module)- Jiri Vencovsky
- Roadmap of Euromyositis - Niels Steen Krogh
- Juvenile dermatomyositis-Helga Sanner, Lucy Wedderburn
- Update from FOREUM approved The IMPROVEMENT project – Hector Chinoy and Lorenzo Cavagna
- Prognosis project – Fabricio Espinosa
- Functional index -3 - Helene Alexanderson
- New classification criteria for myositis- next step – Ingrid Lundberg

## Other activities

A new website is being prepared for MyoNet.

A module to calculate the “2017 EULAR/ACR classification criteria for adult and juvenile idiopathic inflammatory myopathies and their major subgroups” has been developed within the Euromyositis register.

More than 5000 cases from more than 23 centers worldwide have been enrolled in the EUROMYOSITIS registry

## Related publications:

1. Rothwell S, Chinoy H, Lamb JA, Miller FW, Rider LG, Wedderburn LR, McHugh NJ, Mammen AL, Betteridge ZE, Tansley SL, Bowes J, Vencovský J, Deakin CT, Dankó K, Vidya L, Selva-O'Callaghan A, Pachman LM, Reed AM, Molberg Ø, Benveniste O, Mathiesen PR, Radstake TRDJ, Doria A, de Bleecker J, Lee AT, Hanna MG, Machado PM, Ollier WE, Gregersen PK, Padyukov L, O'Hanlon TP, Cooper RG, Lundberg IE; Myositis Genetics Consortium (MYOGEN). Focused HLA analysis in Caucasians with myositis identifies significant associations with autoantibody subgroups. *Ann Rheum Dis*. 2019 Jul;78(7):996-1002.
2. Betteridge Z, Tansley S, Shaddick G, Chinoy H, Cooper RG, New RP, Lilleker JB, Vencovsky J, Chazarain L, Danko K, Nagy-Vincze M, Bodoki L, Dastmalchi M, Ekholm L, Lundberg IE, McHugh N; UKMyonet contributors. Frequency, mutual exclusivity and clinical associations of myositis autoantibodies in a combined European cohort of idiopathic inflammatory myopathy patients. *J Autoimmun*. 2019;Autoimmun. 2019;101:48-55.
3. Lilleker JB, Vencovsky J, Wang G, Wedderburn LR, Diederichsen LP, Schmidt J, Jordan P, Benveniste O, Danieli MG, Dankó K, Phuong Thuy NT, Vázquez-Del Mercado M, Andersson H, Paepe B, De Bleecker JL, Maurer B, McCann LJ, Pipitone N, McHugh N, Betteridge Z, New P, Cooper RG, Ollier WE, Lamb JA, Krogh NS, Lundberg IE, Chinoy H; all EuroMyositis contributors. Response to: 'Antisynthetase syndrome or what else? Different perspectives indicate the need for new classification criteria' by Cavagna et al. *Ann Rheum Dis*. 2018 Aug;77(8):e51